Current and Future Services to Support Young Adults with Type 1 Diabetes in Australia

Steven Brian Ernest James RN, CDE

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Supervisory team:

Lin Perry PhD, MSc, RN

Robyn Gallagher PhD, MN, RN

Julia Lowe MBChB, FRCP, MMedSci

Certificate of original authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of student: Date: 2nd May 2017

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Abstract

Background

Many interacting factors inherent in the young adulthood development stage can limit type 1 diabetes self-management and sustained engagement with diabetes healthcare services, increasing the risk of premature morbidity and mortality in this population. One potential solution is the use of technology, providing additional opportunities to support disease management, maintain and improve communication and engagement with healthcare services. This thesis aims to explore current and future services to the support of young adults with type 1 diabetes in Australia.

Methods

Mixed research methods were used to undertake six studies. A systematic literature review of young adults with type 1 diabetes' vascular complication prevalence and factors predictive of their development was conducted, followed by an assessment of these aspects and healthcare services use in an Australian context through a case note audit. A survey of young people with type 1 diabetes and their parents explored attitudes, perceptions and experiences with diabetes management to identify any challenges, and the proportions transitioning to adult-based diabetes healthcare services potentially requiring support for continuous subcutaneous insulin infusion use. The perspectives of healthcare professionals relating to the support context for patients with type 1 diabetes using or considering this method of insulin delivery, as well as contextual influences for healthcare professionals and their patients, were then examined through semi-structured telephone interviews. Finally, diabetes educators' intentions and reported use of common diabetes-related technologies were identified through a web-based survey, and a subset of survey participants' perceived experiences,

supports and barriers to common technology use were explored through semi-structured telephone interviews.

Results

Few published studies have assessed vascular complication rates in young adults, or factors predictive of their development. However, limited evidence indicated such complications were common. Where assessed, vascular complication rates in an Australian context were like those reported globally and predicted by diabetes duration along with glycaemic control; hypertension was linked with renal function. Important indicators of services not meeting needs were found for young people and young adults, in that routine preventative service usage was low and unplanned acute service usage high. Further, young people with type 1 diabetes and their parents reported experiencing sub-optimal management outcomes. Continuous subcutaneous insulin infusion therapy did not appear to be used to its full potential, with a large proportion intending to use this technology when accessing adult-based diabetes healthcare services.

Healthcare professionals highlighted the complexity of providing support around use of continuous subcutaneous insulin infusion therapy and other common diabetes-related technologies. Intentions were higher than current use, which was unlikely to provide significant support to people with type 1 diabetes. Use of technology in the care of patients with type 1 diabetes was overwhelmingly perceived as burdensome and thus likely to inhibit engagement. Care provided was usually well-intentioned, but often fragmented and inconsistent. Technology benefits are yet to be fully realised because of difficulties with technology access, service co-ordination and insufficient range of healthcare professional expertise.

Conclusions

Thesis findings provide a multi-perspective insight into Australian healthcare services and their gaps for young adults who have type 1 diabetes. In this age group, vascular disease complications occur frequently, as do acute hospital presentations and admissions with secondary prevention services appearing often either under-utilised or inadequate for purpose. Healthcare professionals provide a source of expert care and new technologies provide innovative solutions. Policy and practice innovation is required to better support young adults with type 1 diabetes, especially outside metropolitan areas. The need for consistent and coordinated care, and increased use of common diabetes-related technologies should be a leading focus.

Definitions

Term	Meaning
Young adult	Age range 18 - 30 years
Young people	Age less than 18 years

Abbreviations

Variable	
ACR	Albumin to creatinine ratio
Apps	Smartphone and tablet applications
BMC	BioMed Central, a suite of open access publications
BMI	Body mass index
CGM	Continuous glucose monitoring systems
CI	Confidence interval
CSII	Continuous subcutaneous insulin infusion
GFR	Glomerular filtration rate
OR	Odds ratio
PDSMS	Perceived Diabetes Self-Management Scale
SD	Standard deviation
TAM	Technology Acceptance Model
YOuR-Diabetes	Youth OutReach for Diabetes, a nationally funded project

CHAPTER 1. INTRODUCTION

Overview

The young adulthood developmental stage heralds significant life changes [1-6]. Characterised by physiological, psychological and social transitions, competing demands and challenges may distract or deter young adults with type 1 diabetes from disease self-management and sustained support through engagement with diabetes services; as a consequence their risks for premature morbidity and mortality may be considerably increased [7]. One potential solution may be the use of technology, which can provide additional opportunities to support disease self-management, and to maintain and improve communication and engagement with healthcare services.

The aim of this thesis is to examine the current state and future opportunities for Australian healthcare services to support young adults with type 1 diabetes in disease self-management. It will address the following:

- The diabetes-related outcomes currently achieved by young people and young adults with type 1 diabetes; and
- The experiences and perceptions of healthcare professionals providing care to the type 1 diabetes population, related to the use of common diabetes-related technologies.

Recommendations to support future policy and practice development are provided, which may assist clinicians, diabetes services (including their managers), managers of healthcare organisations, policy-makers and external stakeholders, to better support young adults with type 1 diabetes.

Background

Incidence and prevalence

Type 1 diabetes incidence is increasing globally, particularly in children and young people aged less than 15 years [8]. The cause of this increase remains unclear. It is believed that type 1 diabetes occurs due to an interaction of genetic predisposition and environmental factors, with hygiene, viral, vitamin D deficiency, breast and cow's milk hypotheses being amongst the most well-known theories to explain the lability in the immune system which leads to autoimmunity of the pancreatic beta-cells. There is some suggestion that a multifactorial process may be involved [9, 10].

Contrary to international trends, the incidence of type 1 diabetes in Australia has remained stable for more than a decade at around 10 - 13 cases per 100,000 population, each year [11]. Variations occur across geographical areas and ethnic groups, with rates higher for males (12 versus 9 cases per 100,000 population), and children and young people. Over half of all new type 1 diabetes cases in Australia occur in people aged under 18 years, with rates three times higher among those aged less than 15 years (24 versus 8 cases per 100,000 population), lower than estimates for countries such as Finland (at 62.3 cases per 100,000 population) but similar to the United Kingdom and Canada (at 28.2 and 25.9 cases per 100,000 population per year, respectively) [8].

The prevalence of type 1 diabetes in this age group has also remained stable during recent years. In 2013, this equated to 139 cases per 100,000 population, almost identical to the 138 cases per 100,000 population reported in 2008 [12, 13]. As detectable complications of childhood-onset type 1 diabetes become evident after only around 12 years disease duration [14], high rates of type 1 diabetes in children and young people

means potentially greater numbers of people in the population developing and progressing acute and chronic disease complications at earlier ages, and ultimately premature mortality.

Complications

Vascular complications arise in type 1 diabetes as a consequence of disordered activity of lipid metabolism enzymes or transporters, which then disturb endothelial function, inflammation, coagulation, platelet activation and fibrinolysis [15]. In combination with other population-wide cardiovascular and athero-thrombosis risk factors, vascular complications can lead to a state of persistent and progressive damage to the vascular wall (macro-angiopathy) [16]. In the presence of renal dysfunction and autonomic neuropathy, macro-vascular disease increases the risk of myocardial infarction and stroke [17]. Micro-angiopathic disease also occurs, affecting the eyes, kidneys and peripheral nervous system, resulting in, for example, reduced vision, blindness, renal failure and amputations [17].

Glycaemic control

During the mid-20th century the cause of micro-vascular complications of type 1 diabetes was debated. Some clinicians considered they occurred as a result of non-physiological hyperglycaemia; others thought micro-vascular complications were a glycaemia-independent diabetes feature [17-20]. The crucial importance of glycaemic control in preventing or delaying the onset of disease complications in patients with type 1 diabetes was established in the landmark Diabetes Control and Complications Trial [21]. Conducted from 1983 - 1993, the Diabetes Control and Complications Trial was a controlled clinical study which aimed to determine the impact of intensive

therapy, designed to achieve glycaemic control as close to the non-diabetes range as safely possible. Participants were randomised to either conventional or intensive therapy. Conventional therapy entailed administration of a subcutaneous insulin injection once or twice daily, whereas intensive therapy entailed three or more daily subcutaneous insulin injections, guided by blood glucose monitoring, or use of a continuous subcutaneous insulin infusion (CSII; pump therapy). Intensive glycaemic control was found to reduce the adjusted mean risk of retinopathy development by 76%, of progression by 54%, and development of proliferative or severe non-proliferative retinopathy by 47%. Further, occurrence of micro-albuminuria (urinary albumin excretion greater than or equal to 40 mg/24 hours) was reduced by 39%, macro-albuminuria (urinary albumin excretion greater than or equal to 300 mg/24 hours) by 54%, and neuropathy by 60%. However, there was also a three times higher incidence of severe hypoglycaemia in some patients.

Over 90% of the Diabetes Control and Complications Trial participants were followed in the ongoing longitudinal, observational Epidemiology of Diabetes Interventions and Complications study. A period of intensive glycaemic control in type 1 diabetes was shown to accrue benefit with decreased risk for non-fatal and fatal cardiovascular events [22, 23], with benefit persisting, a phenomenon termed ‘metabolic memory’. However, while significant, the benefit decreased over time [17, 24-27]. Other components of hyperglycaemia, such as glucose variation, may contribute to disease complications risk but only explain a small part of the risk difference between conventional and intensive therapy [28]. Glycaemic control is important for the impact on complications, and in addition poor diabetes control may also incur financial costs.

Financial cost to Australia

The costs that arise from type 1 diabetes are high, and increase substantially with the presence of disease complications [29-32]. DiabCo$t Type 1, a retrospective, cross-sectional, self-reported survey of people with type 1 diabetes aged five years and older in Australia, reported the total annual cost of the disease at between $430 - $570 million in 2004 - 2005: $3,468 per person without complications, $8,122 for those with micro-vascular complications only, $12,105 for those with macro-vascular complications only, and $16,698 per person for those with micro- and macro-vascular complications [29]. The largest contributors to direct healthcare costs were hospitalisation (47%) and medication, involving insulin (13.9%), oral hypoglycaemic agents (0.3%) and other medications (17.7%), with cost of specialist (7.7%), allied health (4.8%) and primary care (3.7%) contributing substantially less. However, many additional factors were not included in these estimates including community resources utilised and out-of-pocket expenses so the real costs are higher.

The potential impact of type 1 diabetes on morbidity, mortality and financial costs reinforces the importance of optimal disease management and appropriate healthcare support [1, 7, 33]. Skilled health support should be available to people with type 1 diabetes throughout their lifespan, including during the vulnerable transition period from paediatric to adult care, and the young adult years because of the significant life changes occurring at this time. This age is also important because this is when habits for adult self-management are established [1-6, 10, 34-37]. The precise nature or age range of this developmental stage has been the subject of debate in developmental psychology [2-6].

Young adulthood

The developmental stage directly following adolescence (i.e. ages 18 - 30 years) has, according to western/developed country notions, traditionally been defined as 'young adulthood' [2, 3]. However, contemporary thinking is that young adulthood does not commence until youth are in their late twenties or early thirties. The stage between the ages of 18 - 25 years instead defines a period termed 'emerging adulthood', an age span which may differ among societies and cultures [4-6]. The term 'young adulthood' is deemed unsuitable as this implies that at this developmental stage, adulthood has been reached. Many people at this age do not perceive themselves as being an adolescent nor entirely an adult [4-6]. For this thesis, however, the term 'young adult' is used to cover ages 18 - 30 years. The rationale for this is that, firstly, the term 'young adult' is more commonly used in research literature. Secondly, the predominant causes of mortality in type 1 diabetes change distinctly at the age of 30 years; the majority of diabetes-related deaths in young adults with type 1 diabetes occur as a result of hypoglycaemia or ketoacidosis [38], whereas the predominant cause for mortality from the age of 30 years onwards is cardiovascular disease [39]. Where younger populations (less than 18 years) are included, the term 'young people' will also be utilised.

Many people in the young adulthood age bracket move away from their parental home [2, 3]. Young adults may attend university, focus upon career choices and have less structure in their daily routine, including in relation to dietary intake and physical activity. Financial stressors may arise through having to manage general living and financial responsibilities [1], or young adults may become involved in intimate relationships and engage in health risking behaviours such as alcohol consumption, cigarette smoking and illegal drug use [1]. Cross-sectional analysis of data collected

between 2002 - 2007 from six diabetes centres in the United States revealed that few (18%) young adults with type 1 diabetes aged 19 years or older achieved recommended glycaemic targets [40]. More recent case note audit data of young adults (aged 18 - 28 years) with type 1 diabetes accessing five adult-based diabetes services before 30th June 2008 (date range unclear, although data collected spanned 1 - 10 years) in three geographical regions of New South Wales, Australia, revealed that little has changed over time [41]. Of 1,202 HbA1c measurements, a key indicator of glycaemic control representing average plasma glucose levels over the previous 8 - 12 weeks, only 161 (13%) were less than 7%. The competing demands, challenges and distractions of young adulthood may lessen commitment to type 1 diabetes self-management and consistent healthcare, significantly increasing risk for premature morbidity and mortality [7].

The later phase of young adulthood is characterised by increasing stability, with a maturing sense of identity, the formulation of a life plan and assumption of more 'adult-like' societal roles, such as employment, house purchase or maintenance of an intimate relationship [5, 6]. Often influenced by life partners, this phase is typically accompanied by an increasing appreciation of the need for improved health; receptiveness to make necessary improvements can present opportunities for related healthcare interventions [42]. With diabetes-related transitions such as disease diagnosis and complication development having been reported to also impact diabetes self-care and coping strategies [43], there is a need for early and consistent yet flexible healthcare support for the type 1 diabetes population throughout the young adulthood development stage. This is to optimise diabetes self-management and service engagement, and achieve the best possible outcomes [1, 7, 33, 44-46].

Type 1 diabetes healthcare services

The unique health needs of young adults with type 1 diabetes relating to their physiological, psychological and socio-cultural transitions are challenging to both paediatric and adult healthcare systems [1, 7, 33]. The challenge arises because medical systems are arranged separately and differently around children to those for adults, with transition between them not clearly the responsibility of either. This arrangement serves young adults poorly because of key differences between the paediatric and adult systems in their approach and provision of type 1 diabetes care, in the types and amount of support, decision-making, family involvement and consent [10, 47]. In paediatric type 1 diabetes care, consultations and management approaches tend to be holistic, with an emphasis on behavioural and developmental issues. Parents/guardians are typically included according to the individual's knowledge and maturity to make choices. In contrast to this approach, consultations in adult care tend to be of shorter duration, typically focus upon medical issues and future complication avoidance, and are expected to involve patients that can make mature individual behaviour, treatment and health information access choices [7]. Whether this is possible, however, may be influenced by social-cultural issues, including education and social deprivation [48, 49].

'Transition' from paediatric to adult care

Australian recommendations for the care of young adults with type 1 diabetes, particularly around the transition period from paediatric to adult care systems, are available [10, 50]. Care during this transition period has also been the focus of a position statement released by the American Diabetes Association [7]. Despite this, there is a lack of comprehensive benchmarks specific to the care of young adults with type 1 diabetes [51]. As a result, evaluation is limited which deters appropriate

prioritisation of service redesign to promote retention of young adults in contact with healthcare services.

The transition of adolescents and young adults from paediatric to adult diabetes care systems should occur in a purposeful, structured and collaborative manner [1, 7, 10, 36, 42, 50]. The focus of transition should be on disease and healthcare engagement, ensuring knowledge and skills adequacy to enable informed health decision making around disease self-management behaviours, problem-solving and active collaboration with the healthcare team. Intervention should also include the provision of medical and psychological support, with consideration given to general adolescent health and potential educational and vocational issues [1, 7, 10, 35-37, 42, 50]. Key elements for successful transition from paediatric to adult care systems have been identified. These include transfer coordination, flexibility in adult service delivery, reminders and a choice of adult provider [34, 35, 51-57].

Not all diabetes services, however, participate in a structured transitional care program, and where services do participate, this is undertaken in a variety of ways with few evaluating their outcomes and even fewer conducting this in a systematic and rigorous fashion [1, 35, 37, 57-65]. A survey of the International Society for Pediatric and Adolescent Diabetes revealed that only 50% of respondents had structured transition programs to adult-based diabetes healthcare services with the approaches utilised varying widely; only 35% of services had undertaken any evaluation to determine effectiveness [66]. Negative transition experiences have been linked to inadequate transition durations, lack of staff continuity, the presence of trainee doctors, difficulty coordinating multi-disciplinary appointments, consultation time constraints, and

inflexible appointment schedules and timing [36, 52, 53, 57, 59, 62, 64, 65, 67-71]. Though there are many factors beyond individual control that can contribute to disengagement or withdrawal from health-care services, and to the development and progression of disease complications, such as the social determinants of childhood environment, education and socio-economic status [72], inadequacies of these care models increase the risk; disengagement has been reported to occur in up to 71% of young adults with type 1 diabetes [7, 41, 55, 62, 73-75].

The healthcare team

Regardless of age, people with type 1 diabetes should receive care from an expert, collaborative and proactive multi-disciplinary healthcare team [10, 76-78]. Usually situated within a wider diabetes service, the team assumes responsibility for diabetes care provision, including alterations to disease therapies, complication screening and monitoring, and 'sick day' management [10]. Specialist care should be available to people with type 1 diabetes, regardless of age, outside of traditional employment hours, for example, for 'sick days' and to advise on acute care needs and avoid unnecessary use of Emergency Department services [10]. Emergency Department services often lack specialist diabetes knowledge and have policies that pay limited attention to secondary prevention, resulting in potentially unnecessary admissions and missed opportunities to prevent further presentations and admissions.

Diabetes healthcare team membership may be extensive. The ideal diabetes specialist team will include a paediatric or adult endocrinologist, Registered Nurses and Accredited Practising Dieticians both of which specialties may be credentialled diabetes educators, and a psychologist or social worker [10]. Dependent upon needs, other team

members may include exercise physiologists, indigenous health workers and other medical specialists such as neurologists, nephrologists and ophthalmologists [10]. Additionally community partnerships are important, especially when considering young adults with type 1 diabetes, who may experience a wide range of stresses that, whilst not diabetes-specific, impact diabetes management [79]. Regardless of the diabetes healthcare team make-up, the team is required to work collaboratively with the primary care provider and keep them informed of progress [10, 79].

The primary care provider, typically a general practitioner, has a unique role in type 1 diabetes care provision, particularly with regard to providing continuity of care during the period of transition from paediatric to adult care systems [10, 79-81]. Their contribution may include preventive care and attention for day-to-day health issues, such as immunisations, disease complication screening and monitoring, and the provision of psychosocial support [10, 79]. However, the primary care provider will often assume a greater role and responsibility for care provision when there is no accessible adult diabetes service, most obviously in rural and remote communities which are often too small to support specialist multidisciplinary teams [10]. In Australia, location of residence may influence glycaemic control of young adults with type 1 diabetes, with worse control demonstrated in young people living in regional areas of New South Wales following transition from paediatric care [41]. Despite urban and rural Victorian children and youth having similar glycaemic control [82-84], regional Victorian youth appear to have a markedly lower quality of life [82]. Collectively this indicates opportunities for improvements in the care of young people with type 1 diabetes in regional, rural and remote areas.

Regular contact with adult diabetes healthcare services is key to the health of people with type 1 diabetes as it has been associated with decreased HbA1c values [85]. Patients with type 1 diabetes are recommended to be reviewed at least 3 - 4 times per year, irrespective of age, with one major annual review with the multidisciplinary healthcare team [10]. Models of support specifically for adolescents and young adults with type 1 diabetes have been reported as beneficial. Models described have included collaborative university diabetes clinics, negotiated telephone support, patient navigator programmes and technology based communication strategies [86-92]. Information systems which allow for electronic patient registries, reminders, decision support and audits may also support care delivery [79, 93, 94]. Use of technology, applying scientific knowledge for practical purposes, provides opportunities to support type 1 diabetes management, and to maintain and improve communication and engagement with healthcare services.

Health technology

Knowledge of effective management of type 1 diabetes has advanced at an accelerating pace during recent years and includes an increasing range of tools and strategies to maintain glycaemic control. Many therapies are being explored, such as pancreas-kidney, islet and stem cell transplants, and inhalational insulin, although translation into everyday practice is distant [95]. Technology may, however, also provide more realistic alternatives to support glycaemic control, in addition to conventional approaches. Many technologies for people with type 1 diabetes are patient-facing and can be broadly categorised as related to insulin delivery (for instance CSII), to blood glucose monitoring (such as continuous glucose monitoring (CGM) systems), and

communication via smartphone and tablet applications (‘apps’), and video-conferencing. These technologies are rapidly evolving and it is likely that more will be forthcoming in the near future.

Continuous subcutaneous insulin infusion (CSII) therapy

As a method of insulin delivery CSII therapy offers potential to achieve tight glycaemic control, which can avoid or delay the onset of disease complications and thus the major sources of morbidity and mortality. CSII technology simulates natural pancreatic insulin secretion through delivery of basal and bolus meal insulin via a subcutaneous cannula. This method of insulin delivery is more intensive than multiple daily injection therapy and is not appropriate for every patient with type 1 diabetes. Technical capability and a high level of commitment to self-management are required. Safe and effective use necessitates commitment to regular blood glucose monitoring, precise counting of carbohydrates and the adjustment of insulin dosages based upon blood glucose levels, carbohydrate intake and physical activity [96-98]. Compared to conventional multiple daily insulin injections, CSII therapy offers easier and more precise dosing, and greater flexibility via instant adjustments to the infusion to allow for variations in dietary intake, exercise or illness.

Optimal CSII use by people with diabetes almost always requires support from a skilled multi-disciplinary healthcare team. Team roles include formulation and titration of insulin dosage algorithms, and provision of education to achieve the benefits the technology offers. The diabetes healthcare team also have a role in mitigating challenges and risks associated with reliance upon an external device which needs ongoing programming and regular change of consumables, suffers device malfunction

and infusion set/site failures that may increase hypoglycaemia or diabetic ketoacidosis risk. In addition, there is the risk of accidental or intentional device misuse, cannula site irritation and infection [99-102].

Despite the potential benefits of CSII usage, there is little Australian information about the everyday experiences of young people who use this technology, and an absence of information on their intentions towards CSII use once they become adults [103, 104]. The effectiveness of this technology for glycaemic control in type 1 diabetes remains a matter of debate for both children and adults [10, 104-130], although a modest statistically significant difference of -0.2% (95% Confidence Interval (CI) -0.28 to -0.12, $p < 0.0001$) favouring CSII has been reported by the Australian Type 1 Diabetes Guidelines Expert Advisory Group [10]. When considering adults only, the mean difference in HbA1c was reported as -0.16% (95% CI -0.33 to -0.01, $p = 0.06$), again in favour of CSII.

Other benefits of CSII use compared to multiple daily injections have been more clearly demonstrated. These include less fear of hypoglycaemia, improved quality of life due to increased meal-time and carbohydrate flexibility, and greater convenience and discretion of insulin delivery. Decreased mortality and favourable health economic outcomes have also been cited [103-105, 111, 117, 122-124, 126, 131-140]. In Australia, for example, incremental cost effectiveness ratios of approximately $74,147 and $74,661 per quality-adjusted-life-year have been reported for adolescents and adults, respectively [140]. However, cost effectiveness has also been shown to vary markedly according to HbA1c reduction achieved and the patient groups analysed.

In 2011 approximately 10,510 people used CSII in Australia, representing around 10% of the Australian type 1 diabetes population [141]. CSII usage as a method of insulin delivery consistently increased by an average of 107 to 140 new users each month from 2004 - 2010 [141], with the majority (70%) situated in major cities [141, 142]. The rate of CSII usage in Australia is largely comparable to that of Sweden, the Netherlands and Germany [141, 143], though lower than that reported in the United States where rates have been estimated at up to 50% [144, 145]. CSII usage tends to cluster at younger ages. The median age of CSII users was reported to be 27 years, with approximately 19% of males and 14% of females with type 1 diabetes (ages 20 - 24 years) utilising this technology [141]; approximately one in every two CSII users in Australia were under the age of 25, with one third aged under 20 years [141]. The peaks of Australian usage occur in the 10 - 14 years age group; 40% of all new users between 2008 - 2010 were under 18 years of age [141]. The main reasons reported for people with type 1 diabetes choosing to use CSII include perceived improvements to lifestyle and glycaemic control, and deferral or avoidance of long-term disease complications [141, 146].

In the groups in which CSII is likely to be beneficial, usage is affected by many factors. For instance, uptake can be influenced by the capacity of the individual to pay for the device and the availability of expert staff. Therefore, funding policy and related processes are important, and these vary across countries. In Ontario, Canada, for example, a CSII device and related consumables may be provided or subsidised for patients with type 1 diabetes [147, 148]. In Australia, the Australian Government provides means tested funding to facilitate CSII use through its Type 1 Diabetes Insulin Pump Program [149]. In this program, the sum of $6,400 (or 80% of the device cost) may be available to persons with type 1 diabetes aged under 18 years that have an

annual family income under $73,146 or receive Centrelink income support payments; varying support with the 20% co-payment is available for those that qualify for the maximum device subsidy. CSII devices in Australia may also be obtained through private health insurance, which entails a lengthy application process plus hospital admission at the time of CSII commencement. Other routes to CSII include clinical trial enrolment, charitable donations or personal finances. The majority (89%) of CSII users in Australia receive some form of financial assistance to acquire their device, with almost all (97%) using private health insurance [141]. The consequence of this method of purchase is that usage is more commonplace in higher socio-economic areas (14% versus 6%) [141]. Regardless of age, the consumables needed for patients with type 1 diabetes to use CSII technology are subsidised by the Australian Government, subject to eligibility criteria, as part of the National Diabetes Services Scheme; an initiative which includes diabetes-related products at subsidised prices for people with diabetes [150].

Continuous glucose monitoring (CGM) systems

CSII technology is often used in combination with CGM systems, helping to automatically control blood glucose by substituting the endocrine functionality of a healthy pancreas through use of technology. Glucose measurements are most often obtained via an electrode (glucose sensor) inserted under the skin to measure levels of glucose in tissue fluid. Connected to a transmitter, information on blood glucose values, direction and rate of change, and any notification of oncoming hypo or hyperglycaemia is sent via wireless radio frequency to a monitoring and display appliance, often a CSII device. Following recent approval by the United States Food and Drug Administration, the first hybrid closed-loop system will soon be commercially available; intended to

automatically monitor and adjust basal insulin dosages in people with type 1 diabetes [151].

As with CSII technology, CGM use almost always necessitates support from a skilled multi-disciplinary healthcare team. The team's role in device use is to assist interpretation of blood glucose values and patterns, considering the effect of food, physical activity, medication and illness [152], and supporting the user to achieve the greatest benefit from the technology. The diabetes healthcare team also has a role in mitigating the challenges and risks of CGM use. CGM users have reported feeling overwhelmed by the volume of data generated, experiencing increased stigmatisation for their diabetes, and have perceived problems and hassles related to nuisance alarms, pain and body issues [153-156]. Further, parents of children with type 1 diabetes using this technology have reported experiencing anxiety as a result of their greater awareness of their child's glucose levels [154], more night-time awakenings and longer total wake times [155, 157].

The effectiveness of CGM technology for glycaemic control in type 1 diabetes has also not been strikingly or consistently demonstrated, for either children or adults [105]. In a systematic review and meta-analysis, CGM use was associated with a modest reduction in HbA1c (-0.26% (95% CI -0.33% to -0.19%)), without any difference in severe hypoglycaemia [158]. Health economic outcomes also remain unclear, though poor adherence to consistent CGM usage has been a limiting factor for effectiveness during adolescent and young adult years [71, 159, 160]. However, other benefits of CGM use have been more clearly demonstrated compared to conventional blood glucose

monitoring, including decreased weight gain, improved quality of life and increased overall disease management satisfaction [154, 161-168].

There is little information available about use of CGM or sensor augmented pump technology. In Israel, the Netherlands, Sweden and Switzerland, for example, CGM technology has been subsidised or provided for patients with type 1 diabetes, subject to eligibility criteria, for some time [169]. In Australia, however, CGM has historically more often been used sporadically than continuously due to its cost [170]. The Australian Government's recent funding of CGM sensors and transmitters for people with type 1 diabetes aged 21 years or less, as part of the National Diabetes Services Scheme, will likely increase uptake [171]. Consequently, demands on healthcare professionals and diabetes healthcare services to provide appropriate technological support will likely also increase. Funding for CGM technology in Australia may also be obtained through private health insurance, or more commonly through personal finance, charitable donations or clinical trial enrolment.

Smartphone and tablet applications ('apps')

Maintenance of effective communication is vital for efficient interaction among patients, their caregivers and healthcare professionals [1]. Distinct from CGM, mobile and internet developments provide diverse approaches to achieving such interaction, allowing transfer of digital information through use of physical or 'wireless' connections between separate geographic locations. Smartphones and tablets, which include specialised 'apps' downloaded on appropriate devices, are examples of communication technologies. They enable transfer of self-taken blood glucose meter measurements electronically to healthcare providers [172], of particular use to diabetes

healthcare professionals since, besides providing accurate and reliable information on which to base recommendations for care, uploaded data can be graphed and analysed statistically. Apps can also provide timely information on, for example, carbohydrate content of foods to support disease self-management [172-174].

Video-conferencing

Communication may also be enabled through use of video-conferencing, where, for example, telecommunication technologies allow people at two or more locations to communicate by simultaneous audio transmissions and two-way video. This may involve personal communication software such as Skype™ and Facetime® as well as commercial systems managed by healthcare organisations. Video-conferencing provides a medium for continuing education as well as clinical care and has been a means through which young people with type 1 diabetes have re-engaged with specialist diabetes healthcare services [175].

Besides apps and use of video-conferencing, many other forms of communication technologies exist. These include social networking sites, email, and both short and multi-media message services [176]. For healthcare professionals in Australia, the 'My Health Record', an electronic summary of an individual's key health information is also available. Designed to be integrated into existing local systems and available to patients, use may assist with inter-professional communication. However, participation in this initiative is voluntary and translation into everyday practice remains distant [177]. Regardless of the type of communication technology, a common feature is that, for type 1 diabetes, they all allow remote access to specialist healthcare, sparing consumers the time and cost of travel and enabling access to specialist services where there would

otherwise be none, promoting service access that is responsive to patient needs [176]. Access is especially important when considering the competing physiological, psychological and socio-cultural transitions of young adulthood that may influence engagement with type 1 diabetes healthcare services [10, 76-78], in addition to practical barriers such as geographical distance between healthcare provider and consumer, available transport and operational hours of preventative care services [178]. The uptake of communication technologies can, however, be influenced by factors such as mobile and internet coverage. With an estimated 74% of younger adults in Australia using smartphones [179], and 90% of 16- to 24-year-olds reported to have used the internet within the previous three months (70% reporting daily use) [180], the use of communication technologies may be highly acceptable.

Summary

High rates of type 1 diabetes in children and young people means potentially more people developing and progressing acute and chronic disease complications at early ages, and ultimately premature mortality [8, 11]. The complications of type 1 diabetes that are the main sources of morbidity and mortality may be avoided or deferred through good glycaemic self-management, which can be facilitated by age-appropriate multi-disciplinary diabetes specialist team support. Such support is recommended for people with type 1 diabetes throughout their lifespan, but especially during the vulnerable transition period from paediatric to adult-based diabetes healthcare services and young adult (ages 18 - 30) years, which pose particular risks for disease self-management and sustained diabetes service engagement. One potential solution may be the use of technology, which can provide additional opportunities to conventional approaches to

healthcare, to support disease self-management and to maintain and improve communication and engagement with healthcare services.

Despite the challenges to disease self-management and sustained diabetes service engagement that are inherent in the young adult years, there is little information available on diabetes outcomes (morbidity and complication rates) during this age range. There is also little Australian information about the everyday experiences of young people who use CSII, and an absence of information on their intentions towards use of this technology once they become adults. There is similar paucity of information on the experiences and perceptions of healthcare professionals providing care to young adults with type 1 diabetes, including on use of common diabetes-related technologies. Such data are needed to support future Australian policy and practice development, to better support young adults with type 1 diabetes.

CHAPTER 2. UNDERPINNING LITERATURE

Study rationale

The potential for decreased attention to self-management, coupled with infrequent diabetes service encounters or care disengagement, are major concerns in relation to young adults with type 1 diabetes as this may contribute to development and progression of acute and chronic disease complications. However, the impact of poor disease self-management on morbidity in young adults with type 1 diabetes has not been clearly detailed; no review has synthesised the data on the prevalence of vascular complications (retinopathy, nephropathy and hypertension), or factors predicting their development in this demographic. This chapter addresses this gap in knowledge to identify the adverse outcomes experienced by young adults with type 1 diabetes, which supports targeted work for this age group. It incorporates the first published systematic review of these vascular complications and factors predicting their development in this population.

James. S, Gallagher. R, Dunbabin. J and Perry. L (2014).
Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes: systematic literature review.
BMC Research Notes, 7:593, 1 - 11.

This paper is appended at Appendix 1. Updating of the systematic review has not changed the main messages of the findings.

Identification of the prevalence of vascular complications and predictive characteristics provides a benchmark of these complications and related risk factors, informing healthcare professionals to assist them in gathering support and targeting interventions to defer or avert their onset. Data published and presented in this chapter includes Australian data published elsewhere in this thesis, as a result of publication timelines of the journals (chapter 3).

Journal choice rationale

Throughout this thesis, the author employed a number of key criteria in making decisions about publication choice. These criteria included journal quality, article promotion and visibility, and copyright provisions. BioMed Central (BMC) Research Notes, a journal of the BMC publication group, publishes research across all fields of biology and medicine. Their open access, promotion and indexing policies allow maximum article visibility and access to a global audience (Table 1). Collectively, this promotes dissemination, ensuring that the results will be widely read by key opinion leaders in diabetes.

Table 1: BioMed Central Research Notes

Criteria	Why suitable
Journal quality	BioMed Central is one of the earliest, highest profile and universally respected open access publication groups. Rigorous peer review is maintained
Article promotion and visibility	Articles are made freely available online through the journal and BioMed Central homepages, without reader subscription or registration barriers. Articles are included in periodic email article alerts and updates, and are indexed in a wide range of electronic databases (CAS; Citebase; Directory of Open Access Journals; Embase; EmBiology; MEDLINE; OAIster; PubMed; PubMed Central; SCImago; Scopus; SOCOLAR; and Zetoc, and accessible via VMC on SpringerLink)
Copyright provisions	Retention of copyright by the authorship team and subsequent freedom to reproduce and disseminate the work as appropriate

Paper 1

Aims

The aim of this review was to identify the prevalence and factors predictive of development of vascular complications (retinopathy, nephropathy and hypertension) occurring in young adults with type 1 diabetes. For the purpose of this review, the term young adult refers to ages 18 - 30 years inclusive.

Methods

A quantitative epidemiological systematic review was conducted using processes adapted from established review methods set out by the Centre for Reviews and Dissemination [181]. Standards derived from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) were applied [182].

Outcome definitions and recommended measurement methods

Definitions and criteria for 'best practice' screening methods for retinopathy, nephropathy and hypertension were sought. At the time of the initial systematic review, detailed recommendations were available in American, British and Canadian guidelines [79, 81, 183].

Diabetic retinopathy

This signifies the presence and characteristic evolution of typical retinal micro-vascular lesions in an individual with diabetes. Besides micro-aneurysms, blood vessel changes include intra-retinal haemorrhage, and vascular tortuosity and malformation (non-proliferative retinopathy) leading to abnormal vessel development (proliferative

retinopathy). Seven-standard field stereoscopic-colour fundus photography with interpretation by a trained reader is the recommended standard screening for diabetic retinopathy, though direct ophthalmoscopy or indirect slit-lamp fundoscopy through dilated pupil or digital fundus photography may also be used. Treatment with laser photocoagulation surgery prevents vision loss [184-187]. The Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [79] advocates that screening should be undertaken at least annually. However, the American Diabetes Association [81] advocates consideration of lesser frequency (every two - three years) following one or more normal eye examinations.

Nephropathy

This signifies a glomerular filtration rate (GFR) less than 60 mL/min present for three or more months, or any evidence of kidney damage for three or more months regardless of GFR [188]. In addition to any anatomical or pathological abnormalities or glomerular haematuria, it can be revealed by micro- or macro-albuminuria/proteinuria. Screening for nephropathy in adults with diabetes entails estimation of the level of kidney function and assessment of urinary albumin excretion. Serum creatinine should be used to estimate GFR and stage the level of chronic kidney disease. Albuminuria should be determined through a timed/24-hour collection, or through a random spot test to determine albumin to creatinine ratio (ACR). The measurement of a spot urine for albumin, without simultaneously measuring urine creatinine, is susceptible to false negative/positive determinations.

Micro-albuminuria was identified as urinary albumin excretion of either 30 - 299 or 300 mg/day in a 24-hour urine collection, with variations based on differing guidelines [79, 81], or an ACR of 2.0 - 20.0 mg/mmol. Macro-albuminuria (overt nephropathy) was identified as greater than or equal to 300 mg/day if a 24-hour urine collection was performed, or an ACR of greater than 20.0 mg/mmol.

Blood pressure

There has been considerable enduring indecision and criteria changes over the target blood pressure for people with diabetes. At the time of the initial systematic review, recommended targets for people with diabetes were less than 130/80 mmHg [79, 81, 183]. In Canadian, American and one Australian guideline this target is still considered appropriate for either all patients with diabetes, or certain individuals such as younger patients, if it can be achieved without undue treatment burden [189-191]. However, another Australian guideline advocates a raised target blood pressure of 140/90 mmHg [192].

Measurement of blood pressure should be undertaken by trained personnel, with participants in the seated position with feet on the floor and arm supported at heart level, after five minutes of rest. Cuff size must be appropriate for the arm circumference, with elevated values confirmed on a separate day. The American Diabetes Association [81] advocate that blood pressure should be measured at every routine visit.

Literature search methods

MEDLINE (Ovid) and Scopus (which incorporates Embase journals), CINAHL, Science Direct (Elsevier), Google Scholar and Cochrane were searched by the first author to February 2017 to identify relevant articles. The MESH headings 'Diabetes Mellitus, Type 1', 'Diabetic Retinopathy', 'Diabetic Nephropathies', 'Hypertension', 'Prevalence', 'Cross-sectional Studies' and 'Prospective Studies', and keywords 'Type 1 diabetes', 'Insulin Dependent Diabetes Mellitus', 'Juvenile Onset Diabetes Mellitus', 'Retinopathy', 'Eye Diseases', 'Nephropathy', 'Kidney Diseases', 'High Blood Pressure' and Longitudinal Studies' were used. The full search strategy can be viewed in Appendix 2.

In addition, reference lists of all eligible studies were hand searched.

Inclusion criteria were:

- Samples with type 1 diabetes;
- Mean age (plus 1 SD) 18 - 30 years, or where the results for this age range were reported separately from other age groups; and
- English language studies only due to lack of resources for translation.

Exclusion criteria:

- Studies reporting data collected pre 1993 as from this date the definitive Diabetes Control and Complications Trial [21] established that the onset and progression of micro-vascular complications can be significantly reduced by HbA1c management. This changed diabetes management to make glycaemic

control central, and hence management and complication rates may have changed.

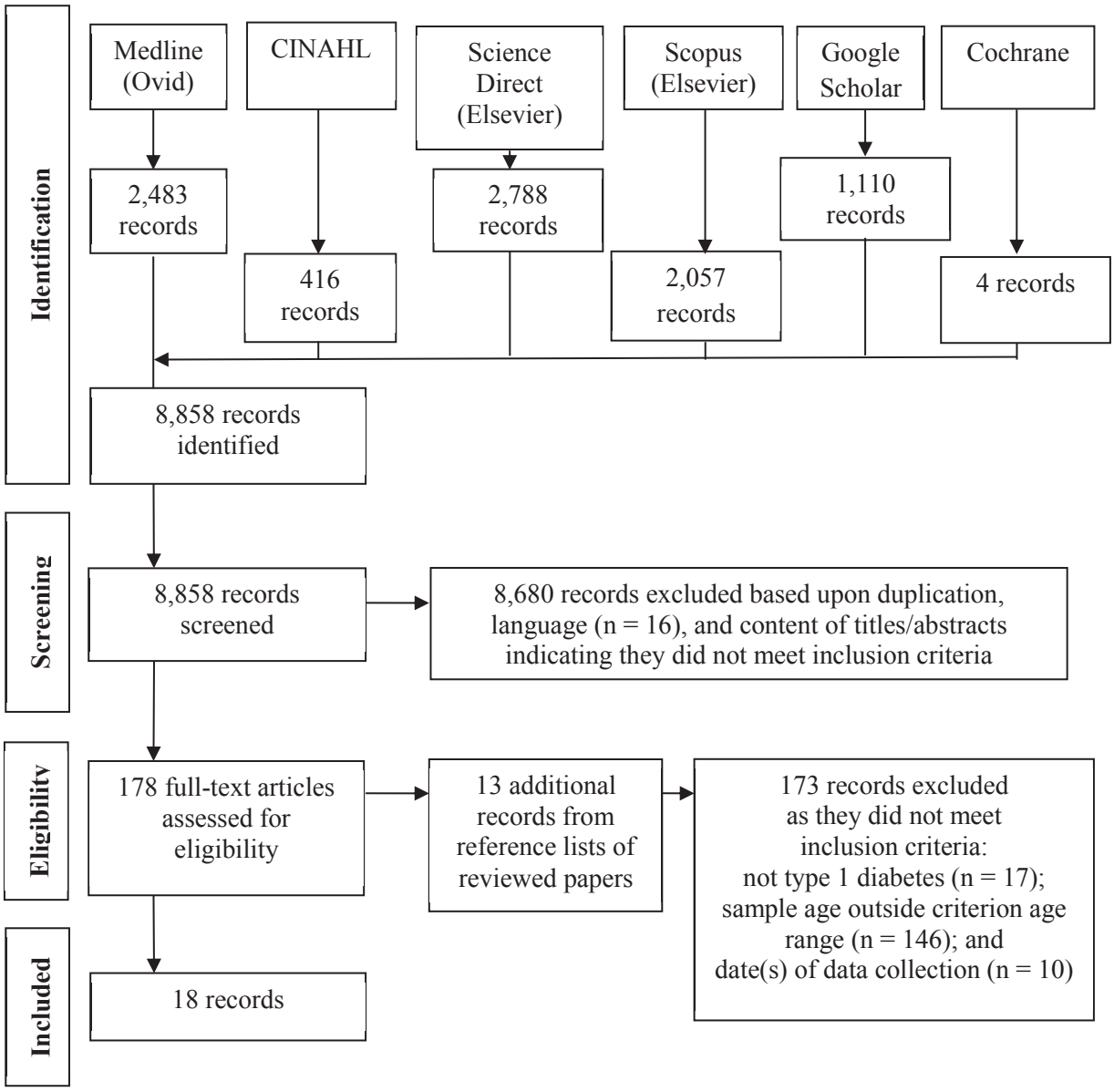
Search outcome

A total of 8,858 records were identified, downloaded to EndNote version X4 and screened by reading titles and abstracts. Of these, 8,680 records were excluded as duplicates or not meeting review inclusion criteria, including 16 non-English language papers. The remaining 178 full-text articles were assessed for eligibility; their reference lists were searched and an additional 13 papers identified. Of these 191 papers, 173 did not meet review inclusion criteria, leaving 18 relevant papers [63, 193-209]. The search process and outcomes are summarised in Figure 1.

Quality appraisal

With no universally accepted 'gold standard' method for evaluating and interpreting epidemiological study quality [210], to determine the strength of evidence quality appraisal was undertaken using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) [211] checklist for cohort, case-control and cross-sectional studies. Eligible papers were also evaluated for methods of assessment and measurement of retinopathy, nephropathy and hypertension in relation to current evidence-based guideline recommendations. This appraisal can be viewed in Appendix 3. To ensure reliability in data extraction and quality appraisal, a sample of papers included in the review were independently appraised and data extraction compared by the second and last authors (six papers each). Agreement was reached for all papers.

Figure 1: Literature search and review flow chart



Data extraction and synthesis

Data were extracted to a purpose-designed spread-sheet in Microsoft Office Excel based on relevant elements of the Consolidated Standards of Reporting Trials (CONSORT) checklist [212]. Extracted data can be viewed in Table 2 and Appendix 4. The number of diabetes centres involved in each study was noted to aid interpretation of transferability of findings.

Results

The 18 papers derived from 13 separate studies and mainly employed cross-sectional research designs; two papers that had provided data applicable to the target age group had involved a cross-sectional documentation survey, and five papers a Danish nationwide longitudinal study. Only 13 of the 18 studies solely provided data relating to the target population; all varied in their methodological quality and are summarised in Table 2, and Appendices 3 and 4. Ethnicity was reported in only three papers, and only one study focused on rural/non-urban populations or localities.

Prevalence and prediction of retinopathy

The prevalence of diabetic retinopathy in the target population was reported in 12 papers [63, 193, 194, 196, 198-200, 202, 205-207, 209]. Prevalence data were reported for 215 applicable participants by Arfken et al. [193], for 137 participants by Casey et al. [206], for both 95 (2010) and 85 (2011) participants by James et al. [196], for 53 by Salardi et al. [202], and for 14 for Steinbeck et al. [63]. In longitudinal studies data were also reported for 324 applicable participants by Broe et al. [194], for 248 participants by Broe et al. [209], for 874 participants by Carlsen et al. [205], for 290 participants at nine

years' diabetes duration by LeCaire et al. [198], and on 190 by Olsen et al. [199], 353 by Olsen et al. [200] and 138 by Rasmussen et al. [213]. Carlsen et al. [205] reported data from 21 paediatric centres, and 31 of 49 clinics from three of the four Norwegian health regions, whereas Casey et al. [206] reported data from one diabetes centre, both Olsen et al. [199, 200] papers from 19 paediatric departments (both) and five/six departments of internal medicine, and Salardi et al. [202] from eleven centres. The other seven papers did not provide detail.

Retinopathy was assessed and measured according to current best practice guideline recommendations in 11 of the 12 papers; it was unclear how retinopathy had been assessed in Steinbeck et al. [63]. In these 11 papers involving seven studies from six different countries with participants sampled by different methods, retinopathy prevalence varied somewhat (Table 2). Casey et al. [206] reported a prevalence of any form of retinopathy of 19%, Salardi et al. [202] an overall prevalence of 40% (with 27% at less than, and 88% at greater than 20 years' diabetes duration), and James et al. [196] prevalence rates of 13.7% (2010) and 9.4% (2011). Olsen et al. [200] reported an a higher overall prevalence of 57.6%, whereas LeCaire et al. [198] reported 47% with retinopathy at nine years' diabetes duration (6% - 73% with retinopathy at mean ages 19.5 - 24.8 years). Finally, Steinbeck et al. [63], who did not detail study assessment methods for retinopathy, reported prevalence rates of 0% at both baseline and at the 12-month follow-up.

Olsen et al. [199] reported a minimal non-proliferative retinopathy prevalence of 48.9%, similar to Rasmussen et al [207] who reported a prevalence of mild non-proliferative retinopathy of 58%, and both Broe et al. [194] and Broe et al. [209] who reported non-

proliferative retinopathy prevalence rates of 61.2% and 51.8%, and 54.6% and 44.4%, respectively (both follow-up participants and non-participants). Carlson et al [205] reported a much lower non-proliferative retinopathy prevalence rate of 13% (2.8% in diabetes duration less than 10 years, 13.6% in diabetes duration 10 - 20 years, and 27.3% in diabetes duration greater than 20 years), whereas Olsen et al. [199] also reported a moderate non-proliferative plus retinopathy prevalence rate of 20%.

Arfken et al. [193] reported a proliferative retinopathy prevalence rate of 10.2%, higher than Carlson et al. [205] who had also reported a proliferative retinopathy prevalence of 3% (0% in diabetes duration less than 10 years, 3.7% in diabetes duration 10 - 20 years, and 10.2% in diabetes duration greater than 20 years). Proliferative retinopathy also affected 0.3% of those at nine years' diabetes duration by LeCaire et al. [198], whereas Broe et al. [194] and Broe et al. [209] reported proliferative retinopathy prevalence rates of 0.5% and 0.7%, and 0.5% and 0%, respectively (both follow-up participants and non-participants).

Table 2: Reported prevalence of diabetic retinopathy

Author(s); country of origin	Number of centres	Age, mean (SD) years unless stated; sample size	Any DR	Non-proliferative DR	Proliferative or treated DR	Predictors
Arfken et al. 1998; U.S.A.	Not provided	19.0 (11.0) years (white) n = 215 (white); n = 312 (TS)			10.2%	Moderate/severe DR (proliferative DR) OR 12.4 (* 5.31 - 28.98) Moderate/severe DR in white participants (proliferative DR) OR 16.55 (* 5.43 - 50.45) HbA1c (2% change) (proliferative DR) OR 1.92 (* 1.36 - 2.7) HbA1c (2% change) in white participants (proliferative DR) OR 2.17 (* 1.34 - 3.5)
Broe et al. 2014; Denmark	Not provided	21.0 (3.3) years (in 1995 study); 20.2 (3.2) years (not in 1995 study)		Participants from baseline 1995 study: 61.2%	Participants from baseline 1995 study: 0.5%	

		n = 185 (participants from baseline 1995 study); n = 139 (non-participants from baseline 1995 study); n = 324 (TS)		Non-participants from baseline 1995 study: 51.8%	Non-participants from baseline 1995 study: 0.7%	
Broe et al. 2014; Denmark	Not provided	Median (SD) 21 (3.3) years (participants); 20.3 (3.2) years (non-participants) n = 185 (participants); n = 63 (non-participants); n = 248 (TS)		Participants: 54.6% Non-participants: 44.4%	Participants: 0.5% Non-participants: 0%	
Carlsen et al. 2016; Norway	21, and 31 of 49 clinics from 3 of the 4 Norwegian	Median (with 10 - 90 percentiles) 23.0 (19.0 - 29.0) years n = 874 TS		13% Diabetes duration < 10 years: 2.8% Diabetes duration 10 -	3% Diabetes duration < 10 years: 0% Diabetes duration 10 -	Non-proliferative $p < 0.05$ when comparing diabetes duration < 10 years and 10 - 20 years, 10 - 20 years and > 20 years, and < 10 years and > 20 years

	health regions			20 years: 13.6% Diabetes duration > 20 years: 27.3%	20 years: 3.7% Diabetes duration > 20 years: 10.2%	Proliferative $p < 0.05$ when comparing diabetes duration < 10 years and 10 - 20 years, 10 - 20 years and > 20 years, and < 10 years and > 20 years
Casey et al. 2014; Rep. of Ireland	1	22.9 (2.0) years n = 137 (TS)	19%			
James et al. 2014; Australia	Not provided	23.0 (3.7) years n = 95 (2010); n 85 (2011); n = 707 (TS)	2010: 13.7% 2011: 9.4%			
LeCaire et al. 2006; U.S.A.	Not provided	9 years diabetes duration: 18.8 (7.2) years (DR -); 21.1 (6.4) years (DR +)	9 years diabetes duration: 47%	9 years diabetes duration: 33% (Min);	9 years diabetes duration: 0.3%	*Age at examination (per year) (DR)* - < 20 years HR 1.2 (* 1.1 - 1.3) ≥ 20 years HR 1.0 (*1.0 - 1.0)

	n = 290; n = 474 TS		11% (M); 2% (Mod - Sev)		*Diabetes duration at examination versus 4 years (DR)* - 7 years HR 1.6 (* 0.8 - 3.3) 9 years HR 4.1 (*2.2 - 7.6) 14 years HR 7.9 (*3.5 - 17.5) *Non-white race (versus white) (DR)* - HR 1.6 (* 0.8 - 3.0) HbA1c (per 1%) by diabetes duration (DR) 4 years HR 1.1 (* 1.0 - 1.3) 7 years HR 1.4 (* 1.3 - 1.6) 9 years HR 1.4 (* 1.2 - 1.6) *Male sex (DR)* - HR 1.3 (*1.0 - 1.7)

Olsen et al. 1999; Denmark	19 and 5^	Median 21.1 (12.0 - 26.9) years n = 190 > 20 years; n = 339 (TS)		Age > 20 years: 48.9% (Min); 20% (Mod plus)		

Olsen et al. 2004; Denmark	19 and 6^	20.4 (3.2) years (prepubertal diabetes onset); 24.2 (1.3) years (pubertal/post-pubertal diabetes onset)
		n = 304 (prepubertal diabetes onset);
		n = 49 (pubertal/post-pubertal diabetes onset);
		n = 353 (TS)
			57.6%			HbA1c (DR); $p < 0.0001$
						Diabetes duration
						before puberty (DR); $p < 0.05$
						after the onset of puberty (DR);
						$p < 0.001$

Rasmussen et al. 2014; Denmark	Not provided	20.6 (3.4) years (overall); 21.1 (3.1) years (DR); 20 (3.7) years (no DR); n = 138		58% (M)		

Salardi et al. 2012; Italy	11	22.0 (4.5) years (very young pre-pubertal onset) n = 53; n = 105 (TS)	40% Diabetes duration - < 20 years: 27% > 20 years: 88%	30% (M); 10% (Mod - Sev)		

DR = Diabetic retinopathy. HR = Hazard ratio. IQR = Inter quartile range. M = Mild. Min = Minimal. Mod = Moderate. n = Number. OR = Odds ratio. Sev = Severe. SD = Standard deviation. TS = Total sample. * = 95% Confidence interval. ^ = 19 paediatric departments and 5/6 departments of internal medicine.

Data were provided relating to predictors of diabetic retinopathy in the target population in only three of these studies. Arfken et al. [193] reported that in white participants, a strong association was demonstrated between the development of proliferative retinopathy and existing moderate/severe diabetic retinopathy (Odds Ratio (OR) 16.55 (95% CI 5.43 - 50.45)). Glycaemic control was also shown to be significant (2% change in HbA1c; OR 2.17 (95% CI 1.34 - 3.5)). This latter finding was consistent with Olsen et al. [200] who reported long-term glycaemic control ($p < 0.0001$) and diabetes duration before and after puberty onset ($p < 0.05$ and $p < 0.001$, respectively) as significantly associated with the development of retinopathy (Table 2). Diabetes duration was also shown to be significant ($p < 0.05$) in the development of non- and proliferative retinopathy by Carlsen et al. [205]. Other findings were generated from samples inclusive of but not specific to the target population.

Prevalence and prediction of nephropathy

The prevalence of diabetic nephropathy was reported in 13 papers [63, 194-197, 199-202, 204-206, 209]. Data were reported for 150 participants by Garg et al. [195], for both 222 (2010) and 218 (2011) participants by James et al. [196], for 86 participants by Salardi et al. [202], and for 121 participants in Kullberg et al. [197]; the number of participants in Raile et al. [201] were unclear. In longitudinal studies data were also reported for 874 participants by Carlsen et al. [205], on 192 participants by Olsen et al. [199], on 339 participants by Olsen et al. [200], and for 182 participants by Marshall et al. [204]. Garg et al. [195] reported data from one eye/kidney clinic and Raile et al. [201] from 262 centres; the number of centres from which data were obtained was unclear in Kullberg et al. [197] and Marshall et al. [204].

Nephropathy was assessed and measured according to current best practice recommendations in five papers [194, 195, 204, 205, 209]; it was unclear how nephropathy had been assessed by Casey et al. [206], James et al. [196], Kullberg et al. [197] and Steinbeck et al. [63]. In these five papers involving four studies from four different countries with participants sampled by different methods, nephropathy prevalence varied somewhat. Broe et al. [194] reported 18 (10.5%) and 17 (14.8%) participants with albuminuria, similar to Broe et al. [209] who reported micro-albuminuria prevalence rates of 7.6% and 7.0% (study participants and non-participants, respectively), and macro-albuminuria prevalence rates of 9.2% and 7.0% (study participants and non-participants, respectively). Carlsen et al. [205] reported a micro-albuminuria prevalence of 10% (9.7% in diabetes duration less than 10 years, 9.3% in diabetes duration 10 - 20 years, and 11.7% in diabetes duration greater than 20 years), and a macro-albuminuria prevalence of 3% (0.6% in diabetes duration less than 10 years, 3.2% in diabetes duration 10 - 20 years, and 3.1% in diabetes duration greater than 20 years). Garg et al. [195] reported 24 (16%) as having an albumin excretion indicative of micro-albuminuria and eleven (7.3%) with values indicative of macro-albuminuria. Conversely, Marshall et al. [204] reported higher micro-albuminuria prevalence rates of 21%, 20.5%, 21.6% and 21.2% (baseline, those who had and had not had an HbA1c measurement after one year, and those who had not had an HbA1c measurement after two years, respectively). Macro-albuminuria prevalence rates of 4.7%, 6.2%, 0% and 3% (baseline, those who had and had not had an HbA1c measurement after one year, and those who had not had an HbA1c measurement after two years, respectively) were also reported.

Casey et al. [206], who did not provide any detail of study assessment methods reported a micro-albuminuria prevalence rate of 5.8% and proteinuria of 0.7%, rates lower than those reported by Kullberg et al. [197]. At recruitment for fundus photography sample ages ranged mean (SD) 12.4 (2.1) - 41.7 (2.4) years, with subgroups A3 aged 21.9 (2.2) years and A4 aged 27.2 (2.3) years. In these subgroups 14% and 13% were reported with urinary albumin excretion greater than 20 mg/L. James et al. [196] reported 15.1% had greater than or equal to one ACR measurement above laboratory threshold value in 2010, whereas 16.1% had greater than or equal to one ACR measurement above laboratory threshold value, and 12.4% greater than or equal to two ACR measurements above laboratory threshold values in 2011. Finally, Steinbeck et al. [63] reported nephropathy prevalence of 0% (baseline) and a micro-albuminuria prevalence of 14.3% (at one year).

Data were provided relating to predictors of nephropathy in only one study [209]. However, this utilised data which involved participants of ages outside of the target population age range.

Prevalence and prediction of hypertension

The prevalence of hypertension was reported in eight papers [195-197, 202-204, 206, 208]. Pinhas-Hamiel et al. [208] provided data from one centre, whereas Schwab et al. [203] provided data from 195 centres. James et al. [196] reported data involving 313 (2010) and 306 (2011) participants, whereas Salardi et al. [202] reported data for 89 participants. Schwab et al. [203] did not detail the number of young adult cohort numbers.

Four papers reported the prevalence of hypertension either without stating or using incorrect diagnostic criteria. Casey et al. [206] reported hypertension occurring in 2.9% of participants, much lower than Pinhas-Hamiel et al. [208] who reported hypertension occurring in 20.8% of participants (16.6% in those of normal weight, 25.8% of those who are overweight, and 64.7% in those who were obese), with 3.7% receiving pharmacotherapy. Schwab et al. [203] reported raised systolic and diastolic blood pressures in 11% and 2.6% of applicable participants, respectively, with 4.8% receiving pharmacotherapy, similar to Broe et al. [194], who reported 5.8% of follow-up participants and 6.9% of non-participants were receiving pharmacotherapy.

Kullberg et al. [197] and Salardi et al. [202] reported hypertension by their definitions (140/90 mmHg) as occurring in 0% - 9% of participants. Garg et al. [195] reported blood pressure values categorised by participants' albumin excretion rate grouping. They reported 34% - 72.5% of systolic and 37.7% - 64.9% of diastolic ambulatory blood pressure measurements (mean of 24-hour collections) as above the 90% percentile of normal for age, gender and ethnic group. For participants with macro-albuminuria, over 60% of day and night-time systolic and diastolic measurements were above the 90th percentile of normal values.

Indices employed by James et al. [196] were in accordance with current best-practice guideline recommendations at the time (130/80 mmHg). Blood pressure measurements were documented in 313 (2010) and 306 (2011) participants, with 33.9% and 30.7% having mean values within hypertensive ranges, respectively. With anti-hypertensive medication prescribed for 10.2% of participants a total of 201 (48.4%) were classified as hypertensive; at least one documented hypertensive measurement was reported in 35

(48.6%) cohort members prescribed anti-hypertensive medication, across the study period. Participants were more likely to have hypertension if they had no (rather than any) health service contact (OR 0.21, 95% CI 0.1 - 0.51, p = 0.001) or a longer diabetes duration (each year, OR 1.05, 95% CI 1.01 - 1.09, p = 0.006). This was in addition to use of CSII (OR 1.8, 95% CI 1.2 - 2.7, p = 0.004) although this latter finding may have been affected by missing data. Marshall et al. [204], who also employed indices in accordance with best-practice guideline recommendations at the time reported similar hypertension prevalence, occurring in 31.8%, 30.8%, 34.7% and 38.6% of participants (baseline, those who had and had not had an HbA1c measurement after one year, and those who had not had an HbA1c measurement after two years). No data were provided relating to predictors of hypertension in this study.

Discussion

This systematic literature review indicated that vascular complications are common amongst young adults with type 1 diabetes although the results reported varied somewhat. Some form of retinopathy occurred in up to almost half of participants; more severe forms affected up to one in ten. Up to one in six was reported with micro-albuminuria; approximately one in 14 had macro-albuminuria. Hypertension occurred in rates ranging between almost one in two participants to approximately one in ten participants. The frequency of these complications is concerning since they are largely preventable, are occurring alongside an increasing incidence of type 1 diabetes worldwide, and incur high costs in financial and health-related quality of life terms. Ng and Morlet [214] flagged the high prevalence and cost of diabetic retinopathy amongst Australians, but failed to differentiate the particular problems of younger onset and

hence greater lifetime burden for those with type 1 diabetes. The DiabCo$t Australia study [29] estimated the minimum annual cost of type 1 diabetes in Australia at between $430 - $570 million in 2004 - 2005, with expenditure increasing with the presence of complications. Real costs were acknowledged as higher, as costs associated with disability and premature mortality were not considered.

Identified prevalence rates of retinopathy in this young adult population were elevated compared to recent data for adolescents with type 1 diabetes. Downie et al. [215] reported a prevalence of 12% between 2005 - 2009, compared to up to 40% and 57.6% in the literature reviewed here [200, 202]. The review rate was not dissimilar to rates provided for older cohorts of people with type 1 diabetes (within a decade outside the review age criteria). Karadeniz and Yilmaz [216], Esteves et al. [217] and Roy [218] reported retinopathy prevalence of 33.2%, 44.4% and 63.9%, respectively; discrepancies perhaps reflected the trend of increasing prevalence of complications with increasing diabetes duration and age.

In studies where data were obtained using current best practice recommendations, prediction of development of nephropathy was not reported for the young adult age group. Studies of older cohorts of people with type 1 diabetes found diabetic nephropathy associated with indices of diabetes duration and control (increasing HbA1c), and with prevalence and severity of other forms of vascular disease and population-wide markers of vascular risk such as triglyceride levels and weight [219-223].

The identified prevalence rates of hypertension in this young adult population were also elevated compared to a study involving a slightly older cohort (mean (SD) age 33.8 (11.8) years at baseline), which reported an increase in elevated systolic and diastolic blood pressures over time. In 2003 - 2004, 17.9% and 6%, respectively, were affected, whereas by 2006 - 2007 this had increased to 28.8% and 8.2%. The proportion of participants prescribed anti-hypertensive medication also increased significantly during this period, from 20.7% to 34.2% [224]. However, in another similarly older cohort (mean (SD) age 37 (9) years) only 48% of those diagnosed and treated for hypertension achieved target values [225], indicating little room for complacency. This is consistent with review findings.

The paucity of blood pressure data for young adults (especially around the time of the initial systematic review) and the indication of poor achievement of treatment goals are particular concerns. Hypertension predisposes to stroke, myocardial infarction, cardiac failure and limb amputation as well as other vascular disease manifestations such as retinopathy and nephropathy. A trend seen in slightly older young adults with type 1 diabetes was of any one end-organ manifestation of vascular disease indicating an increased likelihood of concurrent vascular disease in other areas. For example, in cohorts with mild/severe renal failure, 71.4% and 83.3%, respectively, also had hypertension [226]. The importance of hypertension avoidance when nephropathy is present has particularly been well documented [227-230]. Early detection and prompt treatment are therefore essential, with general population studies clearly demonstrating early diagnosis and adherence to treatment prevents or delays development and progression of end-organ damage [231].

Adherence to sometimes complex, always life-long medication schedules is challenging. ‘Typical’ versus ‘ideal’ medication adherence in patients with hypertension has demonstrated nearly double the relative risk of myocardial infarction, angina and stroke [232]. However, Hill et al. [233] cited achievement of up to 80% adherence rates in routine care and this is especially important for this patient group as cardiovascular disease occurs more than ten times more frequently in those with type 1 diabetes than in age-matched non-diabetes populations [234]. Lack of data on the prevalence of hypertension may hamper prioritisation and appropriate targeting of therapy; important opportunities for treatment may be missed.

Effective prevention interventions rely on identifying modifiable predictors of vascular complications. Data relating specifically to the target population were scarce and this quantitative epidemiological systematic review found glycaemic control as predictive of vascular disease in young adults with type 1 diabetes. Diabetes duration was also flagged, of concern because it is not modifiable and almost half of those who develop the disease do so before age 15 years, many in infancy and childhood [235]. After only nine years with type 1 diabetes almost half of young adults had retinal damage [198] - and probably other vascular disease as well.

On the other hand, glycaemic control is modifiable and influential. The deterioration that accrues with disease duration may be ameliorated by better glycaemic control [21, 236], with better control being achieved by those who maintain contact and relationships with their diabetes healthcare teams [85]. This flags the crucial importance of ensuring that services are able to support young adults with type 1 diabetes, particularly during the vulnerable period when they leave the paediatric services that

supported them as children, establish relationships with adult-based diabetes healthcare services and independent self-management practices. It reinforces the importance of regular screening using best practice methods as this offers the best chance for early detection and initiation of appropriate treatment, and consequently to minimise visual loss and blindness, renal failure and dialysis, heart failure and strokes occurring in young adults.

Good quality data are required from adequately powered studies to inform service development, to help nurses and other healthcare professionals risk-stratify and provide appropriate support to young adults with type 1 diabetes, to minimise and defer onset of vascular complications. In most developed countries, the data required for high-powered studies are collected routinely by diabetes services. That these data have not been accessed and used to develop algorithms to stratify risk for these young adults is indicative of the lack of priority accorded this problem.

Some limitations apply to the current review. A search for grey literature such as conference abstracts was not undertaken; neither were experts in this field contacted for unpublished data, nor authors for data from age specific subsets where these data did not appear in publications. Identification of a specific age range to designate ‘young adults’ was challenging; the focus was on those who would have transitioned out of paediatric into adult care, but use of wider age ranges may have yielded additional data.

Caution also needs to be exercised when considering how review findings can be generalised to the target population of young adults with type 1 diabetes as few studies focused solely on representative samples of this specific age group or involved rural

populations. Other omissions were the paucity of studies undertaken in developing countries, and limited data indicating participants' ethnicity. Finally, although studies reporting data collected pre 1993 were excluded in light of the definitive Diabetes Control and Complications Trial [21], it may have taken a number of years for these research findings to change practice such that glycaemic control became central in every-day management. Earlier literature reviewed may therefore be poorly representative of current practice and not reflect prevalence of vascular complications in today's young adults. New primary research is required.

Conclusions

This is the first systematic review of the prevalence and predictors of retinopathy, nephropathy and hypertension in young adults with type 1 diabetes. While data were limited, underlying vascular disease manifesting as retinopathy and hypertension was common amongst this group, with development predicted by glycaemic control - and probably diabetes duration. With only one of these two factors amenable to clinical management, findings have implications for clinicians, policy-makers, patients and families: to raise the priority of improving glycaemic control as a means to defer and avoid development of complications which otherwise appear near-inevitable.

Clinical messages of this review are the importance of prevention of loss to follow-up and provision of appropriate support, particularly around the vulnerable transition period from paediatric to adult-based care. This would ensure support for optimal glycaemic control and enable regular complication screening to be implemented - essential for early detection and treatment in this age group. Quality data are required to

be available to clinicians and patients to stratify risk and guide treatment planning, and to inform service development. The message for policy-makers is that the prevalence rates identified make good preventive care essential. The challenge is to make this a realistic option and available to all young adults with type 1 diabetes.

Summary

This was the first systematic literature review of the prevalence and factors predictive of vascular complications (retinopathy, nephropathy and hypertension) in young adults with type 1 diabetes, revealing important limitations in the studies reviewed. Few studies specifically recruited this age group, or included representative samples. At the time of the initial systematic review (prior to publication) there were no data from Australia; this was subsequently addressed in the second study of this thesis (chapter 3). An update of the systematic review conducted since the original review was published has also revealed further Australian data and similar findings.

Some form of retinopathy occurred in up to almost half of participants with more severe forms affected up to one in ten. Micro-albuminuria occurred in up to one in six and approximately one in 14 had macro-albuminuria. Finally, hypertension occurred in rates ranging between almost one in two participants to approximately one in ten participants. Few studies sought to determine factors predictive of development of complications, but the factors most consistently reported, particularly amongst older groups, were diabetes duration and glycaemic control. These findings emphasise the importance of improving glycaemic control. Regular healthcare input is therefore important to assist with complication avoidance or early detection and treatment.

CHAPTER 3. THE PREVALENCE AND PREDICTORS OF VASCULAR COMPLICATIONS

Study rationale

A paucity of data generally, and absence of Australian data at the time of the initial systematic review (prior to publication) on the prevalence and predictors of vascular complications (retinopathy, nephropathy and hypertension) in young adults with type 1 diabetes (chapter 2) limits determination and prioritisation of service needs. This chapter addresses this gap in knowledge to identify the adverse outcomes experienced by young adults with type 1 diabetes in an Australian context, a local health district of New South Wales, which supports targeted work for this age group. It incorporates the first published Australian study which identified the prevalence of vascular complications and factors predictive of their development in this population, using data routinely collected by the health service and extracted for the Youth OutReach for Diabetes (YOuR-Diabetes) program. YOuR-Diabetes is a separate program of research which focused on translational models of care for young adults with type 1 diabetes in non-metropolitan locations.

James. S, Perry. L, Gallagher. R, Lowe. J, Dunbabin. J, McElduff. P, Acharya. S and Steinbeck. K (2014).
Service usage and vascular complications in young adults with type 1 diabetes.
BMC Endocrine Disorders, 14:39, 1 - 9.

The paper is appended at Appendix 5.

Journal choice rationale

The rationale for choice of BMC publications was set out in chapter 2. BMC Endocrine Disorders is a journal of the BMC publishing group which publishes research across the prevention, diagnosis and management of endocrine disorders, related molecular genetics, pathophysiology and epidemiology. The 2014/15 impact factor of the journal was 1.71.

Paper 2

Aims

This study aimed to identify the health service usage, prevalence and factors predictive of development of vascular complications (retinopathy, nephropathy and hypertension) in a cohort of young adults with type 1 diabetes in New South Wales.

Methods

This cross-sectional retrospective documentation survey was part of the YOuR-Diabetes project, an Australian National Health and Medical Research Council funded service development and evaluation initiative for young adults with type 1 diabetes in the Hunter New England and Lower Mid-North Coast region of New South Wales. Research partners were the Australian Diabetes Council and Hunter New England Health, the public health service provider for approximately 850,000 residents across 130,000 square kilometres of New South Wales, including metropolitan Newcastle and

regional, rural and remote areas [237, 238]. Specialist services for type 1 diabetes in the region and more widely have been described elsewhere [41, 239, 240].

Participants

Participants were young adults (aged 16 - 30 years) with type 1 diabetes as a primary condition. A database was collated from patient occasions of service with Hunter New England Health services from 2008 onwards, and audited contacts during 2010 and 2011. In Newcastle participants were identified through ambulatory care clinic records and Emergency Department and hospital attendances. In regional areas, records of Community Health, local diabetes educators and pathology services were also searched. Though attempts were made to identify all young adults with type 1 diabetes in the local health district, it was recognised that the database may miss any who did not use state public health services, whose management and outcomes may be dissimilar to those reported.

Data collection

Paper and electronic health records - individual case notes and multi-disciplinary documentation - were reviewed and data extracted using methods developed previously [41]; 95% agreement was demonstrated between two experienced data extractors. Planned and unplanned diabetes-related service contacts were the primary study outcomes: routine diabetes preventive care consultations with a doctor, diabetes nurse educator and/or dietitian, and unplanned presentations at any Hunter New England Health Emergency Department and/or acute hospitalisation for diabetes-related complaints. Emergency Department presentations resulting in hospital admission were solely recorded as hospitalisation. Vascular complications were the secondary study

outcomes. Data extracted included: blood pressure measurements (number; values), ophthalmic examinations (number; documented absence/presence of retinopathy) and urinary ACR measurements indicative of nephropathy (number; values); see Table 3 for definitions [10, 79, 81]. Data related to factors potentially predictive of development of vascular complications were also extracted. Socio-demographic data included age at diagnosis and area of residence [241] as these factors are recognised as impacting access and attendance at diabetes services [55, 85].

Table 3: Study definitions of vascular complications

Complication	**Complication present when:**
Hypertension	Mean systolic or diastolic blood pressure values ≥ 130/80 mmHg, respectively per annum, and/or prescription of anti-hypertensive medication
Retinopathy	Retinopathy documented
Nephropathy	At least one reported ACR measurement above laboratory threshold normal value

ACR = Albumin to creatinine ratio.

Glycaemic control was determined by HbA1c assessments (number; values) classified in relation to an optimal target of less than or equal to 7.0% [10, 79, 81]. As the Australian Diabetes Society [242] advocates HbA1c be maintained at up to 8.0% for those with severe hypoglycaemic episodes or hypoglycaemia unawareness, mean HbA1c was further classified as greater than or equal to 8.0%. CSII use was noted as these devices have potential to improve diabetes management [122].

Data extracted for other factors shown to influence vascular disease risk were: smoking status, weight and height assessments, and Body Mass Index (BMI) calculations (number; values). BMI was firstly categorised as less than 18.5 kg/m^2 (underweight), 18.5 - 24.9 kg/m^2 (on target), 25 - 29.9 kg/m^2 (overweight) and greater than or equal to 30 kg/m^2 (obese) [243].

Ethical approvals for the study were obtained from Hunter New England (HREC 07/09/19/4.01) and University of Newcastle (H-634-1107) (Appendix 6) Human Research Ethics Committees.

Analyses

Data were entered into SPSS© version 21 for analyses. Frequencies, means and standard deviations were used descriptively according to the level of the variable for service usage, vascular complications and potential predictive factors. Relationships were examined between groups with and without vascular complications using Chi-square (X^2) and t-tests; Pearson's correlation coefficients were used between mean systolic and diastolic blood pressure values and potentially linked characteristics such as planned, unplanned and total service contacts, mean HbA1c and BMI values, and diabetes duration. Associations between service usage, age and duration with diabetes were sought using multiple regression. Independent predictors of vascular complications were determined by logistic regression analysis, with separate models developed for hypertension, nephropathy and presence of any of the three vascular complications. For the analysis of these three models only, absence of evidence of documented vascular complications, laboratory values and smoking were treated as absence of that complication or potential predictive factor. No modelling was undertaken for

retinopathy alone as reported cases were too few in number. Predictor variables were determined from the literature review (chapter 2) and preliminary analyses of association. All three models included forced entry of the variables: any planned or unplanned health service contact, sex, metropolitan versus regional/rural residence, CSII use, smoking, mean HbA1c (used as a continuous variable and categorised as less than, or equal to or above 8.0% (over the two years)), and diabetes duration [21, 41, 85, 219, 223, 244-247]; hypertension was included as a variable in the analyses for nephropathy. BMI values were not included in regression analyses as assumptions of the analyses for a linear relationship were violated when used either as continuous or categorical variables. The critical level for retention in the model was set at 0.05. All assumptions of regression analysis were tested and met, including multi-collinearity.

Results

A total of 707 individual case records were identified, with data available for 682 and 707 cohort members in 2010 and 2011, respectively. At the end of the two-year study period the mean (SD) age of the cohort was 23.0 (3.7) years. The sexes were approximately equally represented with 384 (54.3%) male; 39 (5.6%) were documented as Aboriginal and/or Torres Strait Islander. Mean (SD, range) diabetes duration was 10.2 (5.8, 0.2 - 28.3) years, with median 3.0 years of adult service usage. A minority of 299 (42.4%) cohort members lived and 112 (23.1%) accessed services outside of a major city. With no clear record of insulin delivery method for 103 (14.6%) cohort members, 154 (21.8%) were current and 36 (5.1%) intermittent CSII users. The profiles of CSII and non-CSII users differed: CSII users were significantly older (mean age 22.9 versus 21.5 years; $t = 5.011$, $p < 0.001$), had diabetes longer (mean 11.2 versus 9.8

years; $t = 2.886$, $p < 0.004$), received more planned service contacts/two years (mean 11.5 versus 6.25 contacts; $t = 6.535$, $p < 0.001$), more HbA1c measurements/two years (mean 4.2 versus 2.6 measurements; $t = 6.353$, $p < 0.001$), more blood pressure measurements/two years (mean 2.6 versus 1.5 measurements; $t = 5.523$, $p < 0.001$) and more ACR measurements/two years (mean 1.0 versus 0.7 measurements; $t = 3.291$, $p < 0.002$).

Service usage

Routine health service usage was low; 280 (41.1%) and 306 (43.5%) cohort members had no planned service contact recorded during 2010 or 2011. Where a planned service did occur, a median of six individual planned contacts (range 1 - 52) with healthcare providers (i.e. consultations with doctors, nurses and dieticians) were undertaken across the two-year study period.

Unplanned service contacts were common. 308 (45.2%) and 326 (46.1%) members had at least one diabetes-related Emergency Department presentation and/or hospitalisation during 2010 or 2011; of those who had any unplanned contact an overall median of two contacts (range 1 - 22) occurred. Unplanned contacts occurred more frequently amongst those who had evidence of retinopathy or nephropathy: for example, 90% of those who had retinopathy versus only 61.4% of those without documented retinopathy had at least one unplanned service contact. A median of eight (range 1 - 62) planned/unplanned contacts were reported, with 178 and 184 (26.1% in each year) cohort members having no reported service contact, planned or unplanned, and 87 (12.8%) having no service contact over the two years.

There was a significant negative correlation between age and total number of planned contacts/two years (Pearson R = -0.339, $p < 0.001$) and significant but weaker association with duration since diagnosis (R = -0.168, $p < 0.001$; overall model fit $R^2 = 0.120$). Multiple regression analysis demonstrated significant relationships between increasing age and fewer planned contacts (Beta = -0.321, $p < 0.001$), whilst the relationship with diabetes duration was not significant (overall model fit $R^2 = 0.118$). A similar pattern was seen with unplanned service usage (Beta = -0.104, $p < 0.019$); whilst still significant, this was much weaker, i.e. increasing age was more strongly linked with reducing use of preventive care than acute service usage.

Vascular complications

Low levels of screening and/or documentation were recorded but evidence indicated presence of co-morbid disease (Table 4). The majority had no documented blood pressure measurement, ophthalmic examination or ACR measurement during either 2010 or 2011, respectively. Prescription records were unavailable for 269 (38%) and a prescription for anti-hypertensive medication was documented for 72 (10.2%). A total of 201 (48.4%) participants were classified as hypertensive on the basis of at least one documented elevated blood pressure measurement or anti-hypertensive medication prescription. At least one documented blood pressure measurement greater than or equal to 130/80 mmHg was reported in 35 (48.6%) cohort members prescribed anti-hypertensive medication, across the study period.

Table 4: Screening for vascular complications and associated outcomes

Variable	**2010** n (%)	**2011** n (%)
Blood pressure measurements documented	(n = 682)	(n = 707)
At least one	313 (45.9)	306 (43.3)
Mean systolic/diastolic blood pressure	(n = 313)	(n = 306)
≥ 130/80 mmHg	106 (33.9)	94 (30.7)
Ophthalmic examinations documented	(n = 682)	(n = 707)
At least one	95 (14)	85 (12)
Ophthalmic examination reported outcome	(n = 95)	(n = 85)
Retinopathy	13 (13.7)	8 (9.4)
ACR measurements documented	(n = 682)	(n = 707)
At least one	222 (32.6)	218 (30.8)
ACR measurements above threshold value^	(n = 219)	(n = 218)
At least one	33 (15.1)	35 (16.1)

ACR = Albumin to creatinine ratio. n = Number.
^ Three cohort members excluded from analysis for 2010 as measurement undertaken but result unknown.

Of those who had a documented ACR measurement, 137 (40.1%) had two or more and 17 (12.4%) of these had two or more above the threshold value. Those who used CSII were reported to have some form of vascular complication (hypertension, retinopathy and/or nephropathy) at a similarly high frequency to non-CSII users (55.6% affected versus 53.8%), but overall nearly 40% of the sample were eliminated from these analyses due to incomplete data (n = 428 included).

Vascular risk factors

Low levels of documented risk factors were also evident (Table 5). Of those who had any HbA1c measurement a median of three measurements were documented (range 1 -

12) across the two-year study period. In cohort members identified as having hypertension, retinopathy and/or nephropathy, a minority of 67 (36.6%), 6 (30.0%) and 15 (26.8%) had mean recorded HbA1c less than 8.0%, respectively.

Table 5: Vascular disease risk factors

Variable	**2010** n (%)	**2011** (%)
HbA1c documented	(n = 682)	(n = 706)
At least one	422 (61.9)	425 (60.2)
HbA1c value(s) ≤ 7.0% documented in those with ≥ 1 recorded	(n = 422)	(n = 425)
At least one	104 (24.6)	95 (22.4)
HbA1c value(s) ≥ 8.0% documented in those with ≥ 1 recorded	(n = 422)	(n = 425)
At least one	295 (69.9)	293 (68.9)
Mean HbA1c	(n = 422)	(n = 425)
≥ 8.0%	260 (61.6)	269 (63.3)
Weight documented	(n = 683)	(n = 707)
At least one	340 (49.8)	345 (48.8)
Mean BMI	(n = 272)	(n = 255)
< 18.5 kg/m^2	5 (1.8)	4 (1.6)
18.5 - 24.99 kg/m^2	160 (58.8)	137 (53.7)
≥ 25 - 29.99 kg/m^2	69 (25.4)	74 (29)
≥ 30 kg/m^2	38 (14)	40 (15.7)

BMI = Body mass index. n = Number.

Although records of smoking were incomplete for 387 (54.7%), 94 (13.3%) were reported as current smokers. No weight was recorded for 38.8%, and a median one weight assessment per person (range 1 - 11) was documented. Height measurement was not documented for 259 (36.6%).

Associations between risk factors and vascular complications

Cohort members who had retinopathy in comparison to those who did not were significantly older (mean age 24.1 versus 21.7 years, $t = -3.053$, df l58, $p < 0.003$), had longer diabetes duration (mean 14.1 versus 11.0 years; $t = -2.531$, df 143, $p < 0.021$) and more unplanned service contacts over the two-year period (mean 4.4 versus 1.8 contacts; $t = 2.885$, df 22, $p < 0.009$). Cohort members who had any recorded ACR measurement above threshold values in comparison to those who did not were significantly older (mean 23.2 versus 22.0 years; $t = -2.381$, df 332, $p < 0.018$) and had significantly higher mean HbA1c values across the two-year period (9.4% versus 8.6%; $t = -3.174$, df 327, $p < 0.002$). They were more frequently documented with hypertension (68.2% versus 42.0%, $X^2 = 10.2$, $p < 0.001$).

Cohort members were more likely to have documented hypertension if they were male (55.7% versus 41.0%, $X^2 = 9.02$, $p = 0.003$) or had none rather than any unplanned service contact (55.4% versus 44.3%, $X^2 = 9.36$, $p < 0.003$). Higher mean systolic blood pressure values were linked to older age ($r = 0.339$, $p < 0.001$), longer diabetes duration ($r = 0.168$, $p < 0.002$), (unsurprisingly) higher mean diastolic values ($r = 0.639$, $p < 0.001$), greater BMI values ($r = 0.210$, $p < 0.004$), fewer planned ($r = -0.167$, $p < 0.002$), unplanned ($r = -0.169$, $p < 0.001$) and total service contacts ($r = -0.201$, $p < 0.001$). Similar associations were seen with mean diastolic blood pressure values, with higher recordings linked to older age ($r = 0.302$, $p < 0.001$), longer diabetes duration ($r = 0.214$, $p < 0.001$), greater mean HbA1c ($r = 0.178$, $p < 0.001$) and fewer planned ($r = 0.109$, $p < 0.033$) and total service contacts ($r = -0.106$, $p < 0.038$).

Independent predictors of vascular complications

Logistic regression analysis revealed that cohort members were more likely to have hypertension (model $X^2 = 45.34$, df 7, $p < 0.001$) if they had no (rather than any) health service contact (OR 0.21, 95% CI 0.1 - 0.51, p = 0.001), any use of CSII (OR 1.8, 95% CI 1.2 - 2.7, p = 0.004) or a longer diabetes duration (each year, OR 1.05, 95% CI 1.01 - 1.09, p = 0.006). The odds of having nephropathy (model $X^2 = 42.95$, df 8, $p < 0.001$) were increased more than three times by having hypertension (OR 3.19, 95% CI 1.66 - 6.15, $p < 0.001$) and having a mean HbA1c at or greater than 8.0% (OR 3.59, 95% CI 1.67 - 7.74, p = 0.001) (Table 6).

The likelihood of documented hypertension, retinopathy and/or nephropathy (model $X^2 = 58.02$, df 7, $p < 0.001$) increased with absence of health service contact (OR 0.17, 95% CI 0.07 - 0.41, $p < 0.001$), with any CSII use (OR 1.78, 95% CI 1.19 - 2.64, p = 0.005), a mean HbA1c greater than or equal to 8.0% (OR 1.64, 95% CI 1.13 - 2.38, p = 0.01) and longer diabetes duration (each year, OR 1.05, 95% CI 1.02 - 1.09, p = 0.003) (Table 6). Statistical significance was attenuated or lost for these variables when mean recorded values for HbA1c and blood pressure were employed.

Table 6: Predictors of hypertension, nephropathy and any vascular complication (hypertension, retinopathy and/or nephropathy)

Predictor	**Hypertension**			**Nephropathy**			**Hypertension, nephropathy and/or retinopathy**		
	B	95% CI	p value	*B*	95% CI	p value	*B*	95% CI	p value
Any CSII use	1.8	1.2 - 2.7	**0.004**	1.06	0.54 - 2.08	0.877	1.78	1.19 - 2.64	**0.005**
Male	1.42	0.97 - 2.08	0.069	0.58	0.28 - 1.03	0.062	1.16	0.8 - 1.68	0.424
Mean HbA1c ≥ 8%	1.42	0.96 - 2.09	0.077	3.59	1.67 - 7.74	**0.001**	1.64	1.13 - 2.38	**0.01**
Smoking	1.34	0.91 - 1.96	0.135	1.2	0.63 - 2.29	0.572	1.3	0.9 - 1.88	0.17
Diabetes duration	1.05	1.01 - 1.09	**0.006**	0.99	0.93 - 1.06	0.831	1.05	1.02 - 1.09	**0.003**
Metropolitan residence	0.92	0.63 - 1.37	0.69	1.184	0.6 - 2.32	0.623	0.97	0.66 - 1.42	0.868
No reported service contact	0.21	0.1 - 0.51	**0.001**				0.17	0.07 - 0.41	**< 0.001**
Hypertension	N/A			3.19	1.66 - 6.15	**0.001**	N/A		
Constant	0.16		**< 0.001**	0.3		**< 0.001**	0.21		**< 0.001**
Model Statistics	X^2 = 45.34, df 7, n = 550, **p < 0.001**			X^2 = 42.95, df 8, n = 550, **p < 0.001**			X^2 = 58.02, df 7, n = 550, **p < 0.001**		

CSII = Continuous Subcutaneous Insulin Infusion. N/A = Not applicable.
No modelling undertaken for retinopathy independently or analyses of no health service contact as a predictor of nephropathy as too few cases.

Discussion

The study findings are broadly representative across metropolitan, regional and rural Australia as they present data from 707 young adults of a potential 830 people with type 1 diabetes within this age band registered on the National Diabetes Services Scheme (personal communication), a 'best option' source for population figures for this mobile group. Findings demonstrated young adults with type 1 diabetes in this region of New South Wales are at risk of poor health outcomes. Low attendance for preventive care, and shortcomings according to international standards [10, 79, 81] in the screening they received when they attended, reduced sample size for many analyses; consequently, some associations, whilst statistically significant, showed low explanatory power. Nonetheless, data indicated inadequate access/uptake of routine preventive care and increasing age of patients accompanied by a more significant pattern of reducing use of routine preventive care than use of acute services for diabetes crisis management.

Data were indicative or suggestive of co-morbid disease, consistent with systematic review findings (chapter 2). Where assessed, one in six cohort members had at least one recorded episode of micro-albuminuria and as many as one in three had a mean recorded systolic or diastolic blood pressure greater than or equal to 130 mmHg and/or 80 mmHg, respectively; almost one in two were affected when medication for hypertension was included. One in nine had documented retinopathy; less than demonstrated for young adults' in New South Wales between 1990 - 2000 [248], but consistent with more recent New South Wales adolescents' data from 2005 - 2009 [215]. Whilst a reduction in retinopathy prevalence over time may have been related to changes in diabetes management following the definitive Diabetes Control and Complications Trial [21] which made glycaemic control central, low levels of screening

potentially under-estimates the true level of retinopathy in this cohort; also hypertension and nephropathy. Collectively, these data are cause for concern, indicating low use of preventive services reducing with increasing age accompanied by early onset of co-morbid disease, increased risk of impaired quality of life and premature mortality.

Despite guidelines recommending use of angiotensin converting enzyme or angiotensin 2 receptor blockers even in children, few of this cohort were in receipt of treatment or treated to target. Only one in ten were documented as prescribed anti-hypertensive medication; potentially indicating missed opportunities for disease modification. This is particularly regrettable since elsewhere rates of anti-hypertensive prescription have been reported as increasing significantly, to 34.2% in 2007 [224].

Internationally accepted standards for glycaemia management were largely not met [10, 79, 81], with inadequate HbA1c monitoring and two-thirds of cohort members with at least one measurement within the two-year period having mean HbA1c at or greater than 8.0% (64 mmol/mol). Findings are consistent with data from elsewhere in Australia and internationally, in which glycaemic control could not be described as optimal [63, 128, 249, 250]. However, the Epidemiology of Diabetes Interventions and Complications study [251] found similar HbA1c values, increasing in adolescents in the intensive treatment group (from 8.1% to 8.4%) and decreasing (but still elevated) in the conventional treatment group (from 9.8% to 8.5%) after study end. These data suggested it may be difficult to maintain HbA1c values under 8.0% outside a clinical

trial. Data from this location in New South Wales appear consistent with this conclusion.

Findings regarding the use of CSII were noteworthy. Whilst CSII users received overall significantly greater planned service use and assessments, hypertension and any vascular complication occurred more frequently in association with any usage of CSII. Results should be viewed with caution due to missing data but whilst findings were not in line with some studies [122] they were consistent with a previous New South Wales study which showed that while CSII use doubled during the study period, HbA1c in users deteriorated, rising from 8.4% to 8.6% [106]. It is tempting to speculate that perhaps people with poor control of blood glucose, and associated hypertension, may have been started on CSII in an attempt to improve control, but most of these young adults were likely to have commenced use of CSII as children. Education at initiation of CSII for children is primarily to parents/responsible adults. If the child/teen was not targeted for education pre-transition from paediatric care, deficiencies in CSII knowledge were not likely to have been picked up or rectified if the young adult did not have a good relationship with a pump-specialist. Subsidised access to CSII combined with greater access to specialist support for children has resulted in expansion of CSII use particularly amongst children [141], with trends to start CSII use at diagnosis gaining favour. This raises the question how prepared for independent self-management such CSII users are, as they move into adulthood and lose access to paediatric specialist services. Further research is needed to examine whether and how insulin pumps may deliver on their promise of improved diabetes control for people with type 1 diabetes [141]. Given the cost in provision of CSII and the human resources required to support pump users, the possibility that they may not improve outcomes is too important to

ignore. Whilst there may be many reasons for a decline in management of diabetes and its complications in young adults using insulin pumps, one might be that stretched diabetes teams lack adequate specialist resources to provide the more complex and time consuming support needed to optimise results.

Over half of this cohort resided in a major city, and half of those who did not travelled there to access specialist diabetes services. Inadequate access to routine specialist care in regional areas may have contributed to low uptake and increasing attrition with age from routine preventive care services, infrequent screening and suboptimal outcomes. Geographical and socioeconomic factors have been cited as major issues in access to diabetes services, and strong predictors of attendance [55]. Improved diabetes management has been shown by those who maintain contact and relationships with their diabetes healthcare teams [85]. However, this may be a simplistic interpretation. Patterns of use of planned and unplanned service contacts suggest these young adults were not routinely or systematically using preventive services to support their self-care; instead, emergency and acute services appeared to be being used with almost half of cohort members having at least one diabetes-related Emergency Department presentation and/or hospitalisation in 2010 and similarly in 2011. Emergency hospital admission can be seen as an indicator of poor quality of diabetes care [252], with concerns raised at the education provided by healthcare staff in this situation [253].

A chief limitation of this study was use of data originally collected as patient clinical healthcare records; all such studies are forced to rely on professional and legal accountability for clinical record-keeping, and the value attached to record quality in such situations of life-long care. Nonetheless study data will have been affected by

factors affecting the quality of clinical record keeping. Whilst there was potential for Berkson's bias on results, lack of access to general practice or private practice data mean their service episodes were not reflected in these findings except as secondary report within case notes. However, few local general practitioners offered specialist support for type 1 diabetes; a previous qualitative study with this population reported their experience of general practice diabetes care as predominantly age-inappropriate and non-specialist, and private endocrinologists as unaffordable [254]. Thus, this may not have materially affected findings. The two-year time period of the study did not allow for trends across time, and the representative nature of these data can only be estimated by comparison to the earlier study, which revealed that little had changed over time [41]. Study co-morbidity definitions (specifically hypertension and nephropathy) were somewhat simplistic and data were not collected about acute illness and other co-morbidities that may affect screening and disease management. Furthermore, considering the high prevalence of type 2 diabetes in Aboriginal and/or Torres Strait Islander populations [255, 256] a few may have been documented incorrectly with type 1 diabetes based on insulin administration. Nonetheless, the strengths of this study lie with the size of the cohort, the geographical size and range from which the cohort derives, and its near-complete population sampling within this under-researched age group.

Conclusions

Findings flag a need to better understand young adults' drivers and achievements when accessing services, and how services can be reconfigured or delivered differently to engage young adults with age-appropriate care that better meets their needs to achieve

improved outcomes and defer development of complications. In line with national guidelines [10], most type 1 diabetes should be managed by a multidisciplinary specialist health-care professional team, including in the rural and regional setting, where diabetes care may be provided by a locally based paediatrician, physician and/or a Nurse Practitioner on a shared care basis with a multidisciplinary diabetes care team. In many locations, this will require reconfiguration and appropriate apportionment of resourcing of multidisciplinary teams in urban, regional, rural and remote areas, particularly in view of the highly specialist needs of the increasing number of people with diabetes using CSII. Health professionals need to work out ways to enable regular screening to be performed using current best practice guidelines as this affords the greatest chance for early complication detection and hence for initiation of treatment and secondary prevention.

Summary

Analysis of the audited case notes for vascular complications (retinopathy, nephropathy and hypertension) in a cohort of young adults with type 1 diabetes (n = 707) found that routine preventative service usage was low and unplanned contacts high, both deteriorating with increasing age. Vascular complications were relatively common. Where documented, hypertension was particularly prevalent, affecting almost one in two across the study period. However, there are potentially modifiable risk factors. The predictive effect of service contact, and both glycaemic and blood pressure control reinforces their importance for the prevention of vascular complications. As these are presently not being adequately taken advantage of, there is an opportunity for health services to be reconfigured or delivered differently, in ways that meet the needs of

young adults with type 1 diabetes and that are acceptable to them, to achieve better vascular outcomes.

CHAPTER 4. YOUNG PEOPLES' ATTITUDES, PERCEPTIONS AND EXPERIENCES OF DIABETES MANAGEMENT AND CONTINUOUS SUBCUTANEOUS INSULIN INFUSION THERAPY

Study rationale

The everyday experiences of young adults with type 1 diabetes have been well documented, and particularly for those living in Australia. Adults with type 1 diabetes focus on leading a normal life, and want any interruption to employment, social and family opportunities caused by the disease to be limited as much as possible [257]. However, there is evidence that such expectations are seldom met. Young adults with type 1 diabetes have, for example, found it difficult to manage their diabetes in the workplace because of work-related time pressures and the non-routine nature of contemporary work and working environments [258]. Diabetes can also directly or indirectly affect work performance. Hypoglycaemia, a feature of type 1 diabetes management, has been shown to affect driving safety, which may in turn influence employment. Approximately half (52%) of drivers with type 1 diabetes have reported at least one hypoglycaemia-related driving mishap and one in twenty (5%) have experienced six or more within a 12-month period [259, 260]. These mishaps were related to mileage driven, history of severe hypoglycaemia and use of CSII. Risk in driving ultimately reduces the capacity to be licensed to drive, and many related employment, social and family opportunities.

People with childhood-onset type 1 diabetes have also been shown to experience disadvantage in even obtaining employment and to have a lower income in adulthood, although disease-related complications appear to be the most important determinant of

social consequences later in life [258, 261]. Individuals with diabetes-related complications are reported to be twice as likely not to be in the labour force (OR 2.07 (95% CI 1.49 - 2.87)), to have a total income that is 72% that of individuals without diabetes (or only 85% when only considering those with diabetes in the labour force), and receive 58% more social support income [261]. Together these factors can increase psychological distress [262-268], reported in 35.2% of young adults with type 1 diabetes in Australia [263]. Communication and engagement with supportive diabetes healthcare services to promote diabetes self-management are essential to improve the everyday experiences of young adults with type 1 diabetes.

However, there is a mismatch between the need for diabetes services and satisfaction with the services delivered. Many young adults with type 1 diabetes, especially those residing in regional and rural areas of Australia, do not perceive services as meeting their needs [254]. In Hunter New England, New South Wales, young adults with type 1 diabetes reported shortages in specialist and general practice-based care and information, service fragmentation and lack of coordination. Issues of availability and access to expert staff are common, and a survey of people with type 1 diabetes registered with the National Diabetes Services Scheme indicated that rural and regional living respondents were less likely to report consulting an endocrinologist during the past 12 months (RR 0.90, 95% CI 0.83 - 0.97) than those residing in metropolitan settings. Instead, these rural and regional residents often only had access to a (less expert) community practice nurse for their diabetes care (RR 2.22, 95% CI 1.25 - 3.93) [269]. Multiple factors contribute to young adults with type 1 diabetes engaging with

specialist diabetes care: time constraints (30%), transportation (26%), cost (21%) and previous unsatisfactory experiences (27%) have been cited as barriers [265]. Healthcare service redesign is required in Australia, particularly for regional, rural and remote areas, and young adults with type 1 diabetes have expressed their opinion on what is needed.

Young adults with type 1 diabetes have identified a need for ongoing education, age appropriate services and support networks to help them self-manage their diabetes [254]. Professionally led support groups have been shown to improve glycaemic control and self-motivation, decrease self-reported diabetes burden and facilitate peer-to-peer interactions in this population [270]. The needs of adults with type 1 diabetes, especially those utilising CSII therapy, have been identified, with young adults seeking a diabetes team that offers knowledge, support and multidisciplinary expertise, available close to home with after-hours appointment times [52, 257, 265, 270].

The use of technology such as CSII by adults with type 1 diabetes is influenced by many factors outside of healthcare infrastructure and the physical environment. These include the social situation, cultural context and individual differences [271]. CSII is used as a method of insulin delivery by a relatively high proportion of this young adult age group [141], at approximately 19% of young adult males and 14% of females (ages 20 - 24 years) compared to around 10% of the Australian type 1 diabetes population [141]. This is important because CSII use has been consistently shown to improve quality of life for users [136-138, 272-275], which is a major reason why young adults with type 1 diabetes choose this therapy. For example, Kuwaiti young adults (mean (SD) age 34 (8.4 years)) with type 1 diabetes highlighted benefits such as improved

health, mood, emotions, self-confidence and lifestyle flexibility in relation to lifestyle aspects such as exercise, food selection and eating times [136]. The flexibility afforded by this technology may be particularly helpful in situations where eating patterns are inflexible or, for example, culturally driven, such as when fasting during Ramadan. In such situations, CSII use together with adequate counselling and support, has facilitated glycaemic control in young adults with type 1 diabetes [272]. Young adults with type 1 diabetes have repeatedly reported favourable views of CSII use (86% satisfaction rating), with benefits including improvements in lifestyle flexibility and fewer injections [137].

CSII use has also contributed substantially to improvements to quality of life of the parents of people with type 1 diabetes, to glycaemic control and to rates and severity of hypoglycaemia [110-113, 115, 132, 276-279]. However, despite the relatively common use of CSII as a method of insulin delivery amongst children and young people with type 1 diabetes in Australia [141], there is limited information about the everyday experiences of Australians using this technology, or of the intentions of the paediatric population towards CSII use once they become adults [103, 104]. This limits determination and prioritisation of needs in the planning of future adult-based diabetes healthcare services. This chapter addresses these limitations, providing information to support future policy and strategy development. It incorporates a published study which identified the attitudes, perceptions and experiences of diabetes management of young people (12 - 18 years) with type 1 diabetes and their parents living in the Hunter New England area of New South Wales. Findings from young people using CSII were compared to those not using CSII (i.e. delivering insulin via injections). Users' satisfaction with this technology and the proportion likely to transition to adult-based

diabetes healthcare services requiring initiation and/or support for CSII use were determined. Survey data for this chapter originated from the YOuR-Diabetes program.

> Perry. L, James. S, Steinbeck. K, Dunbabin. J, and Lowe. J (2017). Young people with type 1 diabetes mellitus: attitudes, perceptions, and experiences of diabetes management and continuous subcutaneous insulin infusion therapy.
> Journal of Evaluation in Clinical Practice. 4th January (Epub ahead of print).

The paper is appended at Appendix 7.

Journal choice rationale

The Journal of Evaluation in Clinical Practice aims to promote the evaluation and development of clinical practice across medicine, nursing and the allied health professions. The authorship team considered the journal to be suitable based upon its quality, and article promotion and visibility policies (Table 7).

Table 7: Journal of Evaluation in Clinical Practice

Criteria	Why suitable
Journal quality	The Journal of Evaluation in Clinical Practice is a universally respected healthcare publication. Rigorous peer review is maintained and the journal has an impact factor of 1.053 (2015), a reasonable score for a multi-disciplinary journal
Article promotion and visibility	Articles are published online prior to the print edition of the journal publishing, and are included in periodic email article alerts and updates. They are indexed in a wide range of electronic databases (Abstracts in Anthropology; Academic Search; Academic Search Alumni Edition; Academic Search Elite; Academic Search Premier; British Nursing Index; Current Contents: Clinical Medicine; Embase; Health Source Nursing/Academic; HEED: Health Economic Evaluations Database; Journal Citation Reports/Science Edition; MEDLINE/PubMed; PsycINFO/Psychological Abstracts; PSYNX; PubMed Dietary Supplement Subset; Science Citation Index Expanded; and SCOPUS)

Paper 3

Aims

The aim of this study was to explore young people's attitudes, perceptions and experiences with diabetes management, comparing those using with those not using CSII (i.e. delivering insulin via injections), and to estimate the proportion likely to transition to adult-based diabetes healthcare services requiring initiation and/or support for CSII use.

Methods

This was a cross-sectional survey conducted in collaboration with Hunter New England Local Health District (chapter 3) [237, 238]. Ethical approvals for the study were obtained from Hunter New England (HREC 07/09/19/4.01) and University of Newcastle (H-634-1107) (Appendix 6) Human Research Ethics Committees.

Young people aged 12 - 18 years with type 1 diabetes and their parents/guardians residing within the Hunter New England region, were identified through a Hunter New England Local Health District clinical database in 2011. All had access to specialist diabetes care either through attendance at a specialist multi-disciplinary diabetes service located at a tertiary metropolitan children's hospital, or through their regular specialist paediatric outreach program. Initial contact came from recipients' diabetes nurse educators. Packages of introductory letters, information statements, consent forms and the questionnaire were posted to the address recorded in case records. Recipients were asked to return a signed consent form and completed questionnaire in the included

stamped, addressed envelope. In the event of no response one reminder package was posted.

The questionnaire was constructed by research team members and reviewed by local diabetes clinicians (Appendix 8). Most questions were derived from or based on previously developed and validated instruments. The questionnaire contained the Perceived Diabetes Self-Management Scale (PDSMS), an eight-item uni-dimensional measure of self-perceived diabetes self-management efficacy scored as a five-point Likert-type scale (1 = Strongly disagree, 5 = Strongly agree). This measure has previously demonstrated construct, discriminant and predictive validity [280], and in this study a Cronbach alpha of 0.92 indicated internal consistency.

Perceptions of disease knowledge, self-care independence and sense of disturbance (upset or annoyance) caused by diabetes were measured using four questions developed by Viklund et al. [281]. Responses were via visual analogue scales ranging from 0 - 100 mm with five anchor points; higher scores indicated greater knowledge, independence and disturbance, scaling from 'Nothing' to 'Everything' (knowledge) and from 'Never' to 'All the time' (other items).

Demographic data were sought, and residential area was categorised according to the Australian Standard Geographical Classification [282]. Questions sought diabetes-related clinical data to augment identification of young people's experiences, including self-report of HbA1c values, hypoglycaemic episodes, diabetes-related Emergency Department presentations and hospital admissions, and the occurrence of ophthalmic examination and urine checks for renal disease within the past year. Three closed

questions enquired about episodes of CSII dysfunction or discontinuation, and two questions sought to estimate the proportion of paediatric patients transitioning to adult-based diabetes healthcare services in the next five years likely to require CSII initiation, on-going support and monitoring.

Quantitative data were entered into SPSS© Version 22 software for analysis and all test and model assumptions were checked and met. Comparisons were drawn between CSII users versus non-users using appropriate analyses. Four PDSMS items [280] were reverse-coded prior to summation of the eight-item measure. Data for the PDSMS items, perceptions of disease knowledge, self-care independence and sense of disturbance caused by diabetes [281], episodes of hypoglycaemia and service usage were analysed using the Mann-Whitney *U*-test; most recent reported HbA1c values were analysed using the Student *t*-test. Categorical data on self-reported hypoglycaemia, ophthalmic and urine checks, service usage and estimation of proportions of patients likely to transition to adult services requiring CSII initiation and/or support were analysed using the Chi-square or Fisher's Exact test. Analyses pertaining to ophthalmic and urine checks were undertaken on data from all respondents and then, in light of complication screening recommendations for young people, solely for those with greater than five years type 1 diabetes duration [283].

Multiple regression analyses were used to identify predictors of young people's attitudes, perceptions and experiences with diabetes management, with dependent variables of the summary scores for the PDSMS, perceived diabetes-related knowledge, independence in changing insulin doses, independence in care of diabetes overall, disturbance caused by diabetes and most recent reported HbA1c values. In light of the

well-known associations between attitudes, beliefs and behaviours [284], each was also examined as potentially predictive variables. Other potentially predictive variables were selected based upon clinical insights and prior studies: current CSII use (yes/no), sex, age, diabetes duration and metropolitan versus non-metropolitan residence [129, 285]. Data were entered into each model using the backwards method, with missing data deleted listwise. A p value of less than 0.1 was applied for exclusion from the model and less than 0.05 was taken to indicate significance.

Results

Of the 295 questionnaires distributed, 107 (36.3%) were returned partially or fully completed; response rate was difficult to determine as the recorded address may not have been current and not all potential participants may have received the survey. Where reported, 49 questionnaires were completed by a young person alone, four by parents alone and 53 by a young person and parent together. The young people were mean age 15.1 years. The sexes were approximately equally represented with 57.9% male; 5.6% self-identified as Aboriginal and/or Torres Strait Islander. Respondents reported mean age at type 1 diabetes diagnosis and diabetes duration of 9.3 and 5.9 years, respectively. Almost one third (30.8%) resided in metropolitan areas; almost all (91.6%) were full-time students and lived with family members (95.3%) (Table 8). CSII was the current method of insulin delivery for 42 (39.3%) respondents, with a further eight having used this in the past (n = 50, 46.7%); mean (SD) age at commencement was 12.4 (2.6) years. Where reported, current CSII users and non-users differed in that current users were significantly younger at diagnosis, with significantly longer diabetes duration (Table 8).

Table 8: Demographic details and reported glycaemic control

Variable	**Overall** [n = 107 unless stated]	**Current CSII user** [n = 42 unless stated]	**Non-CSII user** [n = 65 unless stated]	**Test value**	**p value**
Full-time student (n%)	98 (91.6)	39 (92.9)	59 (90.8)	-	-
Lives with family members (n%)	102 (95.3)	40 (95.2)	62 (95.4)	-	-
Male gender (n%)	62 (57.9)	24 (57.1)	38 (58.5)	X^2 = 0.018	0.893
Age, mean (SD, min - max) yrs.	15.1 (2.0, 10.6 - 18.8)	15.4 (1.9, 12.3 - 18.4)	14.9 (2.1, 10.6 - 18.8)	U = 1108.5	0.102
Age at diagnosis, mean (SD, min - max) yrs.	n = 104 9.3 (3.7, 0.9 - 16.8)	n = 41 8.4 (3.1, 1.5 - 14.5)	n = 63 9.8 (4, 0.9 - 16.8)	U = 964	**0.029**
Diabetes duration, mean (SD, min - max) yrs.	n = 104 5.9 (3.5, 0.2 - 13.7)	n = 41 7.1 (2.7, 1.7 - 13.7)	n = 63 5.1 (3.7, 0.2 - 12.7)	U = 796	**0.001**
Metropolitan residence† (n%)	33 (30.8)	16 (38.1)	17 (26.2)	X^2 = 1.706	0.192
Most recent HbA1c (%), mean (SD, min - max)	n = 65 8.0 (1.6, 5.2 - 12.9)	n = 28 8.3 (1.4, 6.3 - 11.2)	n = 37 7.8 (1.7, 5.2 - 12.9)	t = 1.454	0.151

† Metropolitan versus non-metropolitan according to Australian Standard Geographical Classification. n = Number.
CSII = Continuous Subcutaneous Insulin Infusion. yrs. = Years. X^2 = Chi-square test. U = Mann-Whitney U-test. t = Student's t-test.

Attitudes and perceptions

Respondents' (n = 86) attitudes towards and perceptions of their diabetes management self-efficacy were largely positive. They mostly agreed that they handled themselves well with regards to their diabetes, could manage things related to their diabetes as well as most others, that they succeeded in the things they did to manage their diabetes, and were able to achieve management plans (Table 9). Mostly, they did not find it difficult to find effective solutions for management problems, efforts to change things about their diabetes worked, typical plans for diabetes management worked out well, and management turned out as planned. Reported attitudes and perceptions were not statistically significantly different between current CSII users and non-users for individual items or the measure summaries (Table 9). Respondents were significantly more likely to report greater self-efficacy for diabetes self-management (have a higher PDSMS summary score) if they were younger, reported greater independence in their diabetes care, were less disturbed by their diabetes diagnosis, and reported lower most recent HbA1c values (Table 10).

Table 9: Attitudes and perceptions (Perceived Diabetes Self-Management Scale - PDSMS)

Variable	**Overall** Median (25, 75) score [n = 86 unless stated]	**Current CSII user** Median (25, 75) score [n = 36 unless stated]	**Non-CSII user** Median (25, 75) score [n = 50]	**Mann-Whitney U test value**	**p value**
Succeed in things to manage	4 (3, 4)	4 (3, 4)	4 (4, 5)	*715*	0.076
Able to achieve plans	n = 85, 4 (3, 4)	n = 35, 4 (3, 4)	4 (4, 5)	*747.5*	0.218
Manage as well as others	4 (4, 5)	4 (4, 5)	4 (4, 5)	*813.5*	0.395
Handle diabetes well	4 (4, 5)	4 (4, 4.75)	4 (4, 5)	*846*	0.607
Effective solutions†	4 (3, 4)	4 (3, 4)	4 (3,4)	*869*	0.777
Doesn't turn out way liked†	4 (3, 5)	4 (3, 5)	4 (3, 4.25)	*887*	0.906
Efforts to change don't work†	n = 85, 4 (3, 4)	n = 35, 4 (3,4)	4 (3,4)	*863.5*	0.914
Plans don't work out well†	4 (3, 4)	4 (3, 4)	4 (3, 4)	*899*	0.993
Summary score	n = 84, 31 (26, 34)	n = 34, 31 (26, 34)	31 (26.75, 36)	782.5	0.537

†Reverse scored. 1 = Strongly disagree, 5 = Strongly agree. CSII = Continuous Subcutaneous Insulin Infusion. n = Number.

Table 10: Multiple regression (backwards entry)

Dependent	**Independence in care of diabetes†**		**PDSMS†**		**Disturbed by diabetes†**		**Independence changing insulin dosages†**		**Most recent HbA1c**		**Knowledge of diabetes†**	
Independent	*B*	p value	*B*	p value	*B*	p value	*B*	p value	*B*	p value	*B*	p value
Sex					0.193	0.060						
Age overall	0.490	**< 0.001**	-0.324	**0.003**					-0.237	**0.04**	-0.341	**0.019**
Metropolitan residence Yes/No					0.213	**0.037**	-0.194	0.059				
PDSMS†	0.255	**0.007**	-		-0.688	**< 0.001**	0.255	**0.044**	-0.632	**< 0.001**		
Knowledge of diabetes†	0.227	**0.015**			0.266	**0.015**					-	
Independence changing insulin dosages†	0.288	**0.004**					-		0.345	**0.005**		
Independence in care of diabetes†	-		0.378	**0.001**			0.535	**< 0.001**			0.572	**< 0.001**
Disturbed by diabetes†			-0.428	**< 0.001**	-							

Most recent HbA1c		-0.302 **0.003**		0.356 **0.004**	-	
Model number, R^2	*7, 0.626*	*7, 0.589*	*7, 0.495*	*7, 0.464*	*8, 0.382*	*9, 0.226*

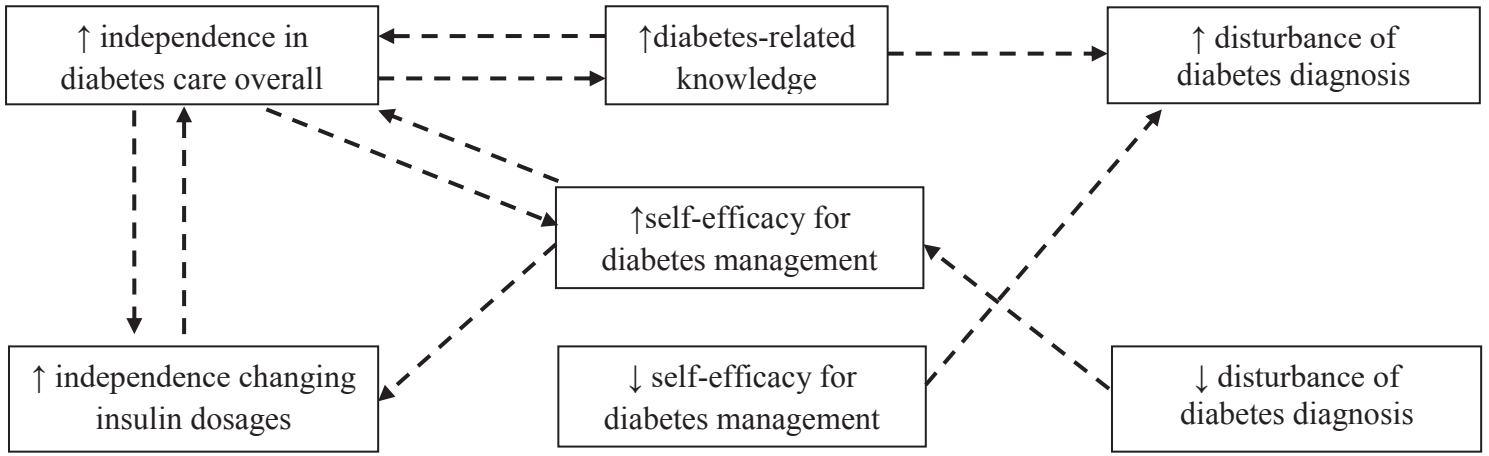
† = Summary score. n59. CSII = Continuous Subcutaneous Insulin Infusion. PDSMS = Perceived Diabetes Self-Management Scale.
The independent variables Current CSII use yes/no and Diabetes duration overall were removed from all models.

Overall, 87 respondents perceived their diabetes-related knowledge as moderate (median (25, 75 quartile) score 75 (63, 76) of 100). Respondents reported changing their insulin dosages independently some of the time (scoring 69 (21, 94) of 100) and that they were somewhat independent in overall diabetes management (scoring 76 (62, 98) of 100). Again, there were no statistically significant differences in responses of current CSII users (n = 36) and non-users (n = 51) for these three items. Respondents were more likely to report independence in changing insulin dosages if they reported greater management self-efficacy (a higher PDSMS score), greater independence in their diabetes care overall, and had a higher most recent HbA1c (Table 10). They were more likely to report independence in their diabetes care overall if they were older, reported greater management self-efficacy (a higher PDSMS score), greater diabetes-related knowledge and independence changing insulin dosages (Table 10).

Experiences

Respondents' (n = 86) indicated they were disturbed by their diabetes for about half the time (median (25, 75 quartile) score of 50 (25, 75)), with no significant difference between CSII users and non-users. Respondents were more likely to report disturbance by their diabetes if they resided in non-metropolitan locations, perceived less self-efficacy to self-manage their diabetes (a lower PDSMS score), and reported greater diabetes-related knowledge (Table 10). Patterns of associations between knowledge, attitudes and experiences of diabetes modelled by regression analysis are illustrated in Figure 2.

Figure 2: Patterns of associations between knowledge, attitudes and experiences of type 1 diabetes modelled by regression analysis



Recent HbA1c values were supplied by 65 (60.7%) respondents; mean (SD, min, max) values were 8.0% (1.6%, 5.2%, 12.9%) (Table 8). Recent values were considered (n = 80) higher than usual by 25 (31.3%), usual for 33 (41.3%) and lower than usual by 10 (12.5%). Whilst there was no statistically significant difference between values reported by current CSII users and non-users (n = 28, mean (SD, min, max) 8.3% (1.4, 6.3, 11.2) versus n = 37, 7.8% (1.7, 5.2, 12.9); t = 1.454, p = 0.151 (95% CI = -0.21, 1.36)), a mean difference of 0.5% might be considered clinically significant. Values were non-significantly higher in respondents who resided in a non-metropolitan location (n = 39, 8.2% (1.7, 6.0, 12.9) versus n = 26, 7.7% (1.4, 5.2, 10.8); t = -1.279, p = 0.206 (95% CI = -1.31, 0.29)).

In the previous month hypoglycaemia was reported by 73 (77.7%) of 94 respondents, who reported experiencing a median (25, 75 quartile) 3 (1, 5) hypoglycaemic episodes per week. There was no statistically significant difference in responses from current CSII users compared to non-users for both any occurrence (yes/no) (n = 28 (75.7) versus n = 45 (78.9%); X^2 = 0.138, p = 0.71) and frequency (2.5 (1.25, 4) versus 3 (1, 5) events). Of 87 respondents, 33 (37.9%) reported having a hypoglycaemic episode that required assistance since their diabetes diagnosis; not statistically significant, these severe episodes were reported by a greater proportion of non-CSII users than CSII users (n = 23, 45.1% versus n = 10, 27.8%). The method of insulin delivery utilised during these episodes was, however, unknown.

When asked about diabetes complications screening within routine care in the previous year, 58 of 87 respondents (66.7%) reported having an ophthalmic examination for retinal disease and 66 (75.9%) reported urine checks for renal disease. Distribution was

similar for CSII users and non-users: ophthalmic examinations (n = 25 (69.4%) versus n = 33 (64.7%); $X^2 = 0.213$, p = 0.644); urine checks (n = 27 (75%) versus n = 39 (76.5%); $X^2 = 0.025$, p = 0.875). Of respondents with greater than five years' diabetes duration (n = 46), 34 (73.9%) reported having an ophthalmic examination and 37 (80.4%) reported having a check for renal disease. However, distribution was not always similar for CSII users and non-users: for ophthalmic examinations (n = 19 (73.1%) versus n = 15 (75%); $X^2 = 0.022$, p = 0.883) and urine checks (n = 18 (69.2%) versus 19 (95%); Fisher's exact = No value, p = 0.057), respectively.

Diabetes-related care was commonly accessed through acute services. Within the previous year, 11 of 92 respondents (12%) reported a diabetes-related Emergency Department presentation, and 27 of 96 respondents (28.1%) reported a diabetes-related hospital admission (excluding an admission for type 1 diabetes diagnosis); overall, 33 respondents (30.83%) had used acute services for diabetes-related problems (excluding for type 1 diabetes diagnosis). Again, there was no statistically significant difference in responses of CSII users compared to non-users (Table 11).

Future preferences

Substantial numbers (n = 39, 41.1%) of the 95 respondents who indicated their future preferences for insulin delivery method intended to use CSII as an adult; this included 31 of 42 (73.8%) current CSII users and 8 (15.1%) of 53 (of 65) respondents not presently using this technology. Although not statistically significant, a greater proportion of those intending to use CSII lived in non-metropolitan settings (n = 25 (64.1%) versus n = 14 (35.9%)). Additionally, 41 respondents either had not thought

Table 11: Service usage

Variable	**Overall** n (%) unless stated	**Current CSII user** n (%) unless stated	**Non-CSII user** n (%) unless stated	**Test value**	**p value**
Any DR ED presentation Yes	n = 92 11 (12)	n = 34 3 (8.8)	n = 58 8 (13.8)	FET = not provided	0.741
DR ED presentations, median (25, 75)	n = 11 2 (1, 4)	n = 3 2 (2,-)	n = 8 1.5 (1, 4)	*U* = 939	0.50
Any DR hospital admission† Yes	n = 96 27 (28.1)	n = 39 11 (28.2)	n = 57 16 (28.1)	X^2 = < 0.001	0.988
DR hospital admissions†, median (25, 75)	n = 27 1 (1, 1)	n = 11 1 (1, 1)	n = 16 1 (1, 1)	*U* = 67.5	0.318
Any DR acute service usage† Yes	n = 100 33 (33)	n = 40 13 (32.5)	n = 60 20 (33.3)	X^2 = *0.*008	0.931
DR acute service usage†, median (25, 75)‡	n = 20 1 (1, 3.75)	n = 5 1 (1, 2.5)	n = 15 1 (1, 4)	*U* = 31.0	0.612

†Excluding admissions for type 1 diabetes diagnosis. ‡Data excluded from analysis where not present for both ED and hospital admissions.
CSII = Continuous Subcutaneous Insulin Infusion. DR = Diabetes-related. ED = Emergency Department. n = Number.
FET = Fisher's Exact Test. X^2 = Chi-square test. *U* = Mann-Whitney *U*-test.

about it or could not anticipate their future plans, with 10 (23.8%) current CSII users planning to discontinue this method of insulin delivery.

Discussion

The majority of children and adolescents with type 1 diabetes had positive attitudes and perceptions of their self-efficacy and diabetes management, but were moderately disturbed by their diabetes and experienced sub-optimal management outcomes. Overall there was no statistically significant difference in responses from CSII users and non-users. A large proportion of respondents indicated that they intended to use this therapy when accessing adult diabetes services; information of value for comprehensive health service and education planning.

Findings indicate the inter-related roles of perceived self-efficacy, diabetes-related knowledge, independence in diabetes management and sense of disturbance caused by diabetes (Figure 2). However, the influence of age appeared complex. Perhaps younger respondents perceived they had better diabetes self-efficacy and knowledge because they were shielded by their parents' contribution to their management; consistent with increasing independence in diabetes care overall with increasing age. With greater diabetes knowledge linked with greater sense of disturbance by their diabetes, education needs to be tailored to achieve better self-management, as it may otherwise function to cause anxiety or distress and may result in worse outcomes. The suggestion of greater disturbance in non-metropolitan residents was perhaps linked to the greater isolation and lack of peer support experienced in rural and remote areas [254] and warrants further exploration.

Overall, the patterns of glycaemic control reported by these participants could not be described as optimal (chapter 2) [10, 79, 286]. Findings were consistent with previous studies of young adults with type 1 diabetes in this region of New South Wales (chapter 3) [41] and elsewhere [287-289], and are cause for concern, especially considering the accompanying positive attitudes, high perceived self-efficacy and diabetes self-management abilities also reported. High rates of hypoglycaemia and acute healthcare service usage for diabetes-related problems were also consistent with findings from young adults with type 1 diabetes (chapter 3) [41]. CSII use did not appear to confer a significant advantage in glycaemic control, although this study lacked statistical power to demonstrate this. However, findings highlight the importance of good preparation and support for CSII use.

There is broad consensus that a prospective CSII user should be assessed by a multidisciplinary team in relation to multiple criteria to ensure appropriate targeting of this technology [97, 141]. In this study, it is unclear whether and how this, and re-evaluation post commencement, occurred. Respondents' CSII use (39.3%) was broadly consistent with national data, supporting the generalisability of findings in this young population; one third of people with type 1 diabetes aged under 20 years across Australia are reported to use CSII technology [141]. Eight current non-users had used CSII in the past. Varied rates of discontinuance have been reported, and although up to 18% of children and young people have been reported to discontinue CSII within the first few years of use [129, 290], lower rates have also been reported [291, 292]. Given the cost to provide CSII and the human resources required to support CSII users, discontinuance and any failure to improve real life clinical outcomes are disappointing

[105]. One reason for sub-optimal outcomes might be that stretched diabetes teams, especially in rural areas, lack adequate specialist resources to provide the more complex and time-consuming support needed to optimise results. Where this is the case, service redesign is required to improve support particularly but not exclusively for CSII users. Other technologies such as video-conferencing may also be of benefit [175], and should be explored.

Limitations of the study include the use of self-report data, and sampling from only one regional health service. The sample size was relatively small and the survey entailed only brief assessments of perceived disease knowledge, self-care independence and sense of disturbance caused by diabetes. No data were available on participants' and their parents'/guardians' economic status, and it was therefore not possible to consider whether financial concerns such as lack of access to private insurance or loss of the Australian Government subsidy for a CSII device at age 18 years may have, for example, influenced access or intention to use CSII [293]. The survey was completed, variously, by the young person, their parents, or both; findings therefore contain a mix of the young person's independent views and what the parents think their views are. The intention was to obtain the views of young people and it was accepted that some parental input might be needed to obtain this, even to the extent of a parent responding as proxy. The strengths of the study derive from successfully recruiting a 'hard to access' group across a wide and diverse geographical and sociological area, most of whom completed the survey unaided. Incremental changes in technology since the study was undertaken are unlikely to yield different findings.

Conclusions

Opportunities for enhanced diabetes service support were identified, with CSII in particular not currently appearing to achieve its full potential. Service structure needs to keep pace with the changes in technology and its rapid uptake by young people. Policy-makers and managers should align service delivery to patient goals and preferences to maximise service as well as patient benefit. This must include regular access to multidisciplinary team support with specialist medical input, which is particularly lacking for CSII users and those outside metropolitan areas.

Summary

Findings from the postal survey of young people (12 - 18 years) with type 1 diabetes and their parents (n = 107) provide insights into their attitudes, perceptions and experiences of diabetes management. Over one in three (39.3%) respondents utilised CSII as a method of insulin delivery; broadly consistent with national figures of one third of people with type 1 diabetes aged under 20 years using CSII technology [141], which supported the generalisability of findings in this young population. Young people with type 1 diabetes and their parents had generally positive attitudes and perceptions of their self-efficacy and their diabetes management, but they were moderately disturbed by their diabetes and reported experiencing sub-optimal management outcomes. CSII users were general satisfied with this technology, but there were no statistically significant differences in outcomes between users and non-users. Collectively, findings highlight the need to determine how young people's positive attitudes and perceptions of their self-efficacy and diabetes management can be supported in an adult diabetes service. The findings reinforce the need for young people to have adequate information

to make decisions about healthcare as an adult and indicate care expectations around CSII therapy.

In this survey, a large proportion (41.1%) of respondents intended to use CSII as a method of insulin delivery when accessing adult-adult diabetes healthcare services, information which is of use for comprehensive health service and education planning. In the previous paper, auditing case note data of young adults with type 1 diabetes, 26.9% were CSII users (chapter 3). This supports the contention that diabetes healthcare services are about to see an increase in use of CSII technology and need to prepare for the increased service support that effective use entails. A substantial amount of time and skill are required by healthcare professionals to successfully implement, adjust and monitor this method of insulin delivery [98]. Without appropriate support, CSII use cannot be expected to deliver the better outcomes that the literature indicates is achievable.

CHAPTER 5. HEALTHCARE PROFESSIONALS' EXPERIENCES WITH CONTINUOUS SUBCUTANEOUS INSULIN INFUSION THERAPY

Study rationale

The previous papers indicate an adult diabetes service facing difficulty in meeting the increasing service support demand for CSII use; this is the case for many such Australian healthcare services [98]. Patient disengagement from specialist diabetes healthcare services may follow and result in compromised diabetes self-management (chapters 3 and 4) [41]. However, despite these well-known service and staffing concerns, there is little information available to indicate what is required of healthcare professionals to support patients interested in or using CSII therapy, and what are the experiences and perspectives of the healthcare professionals responsible for delivering this. This information is needed to understand how services are currently delivered, for comprehensive service and education planning, particularly for patients living outside metropolitan areas. This chapter addresses this limitation, providing information to support future policy and strategy development. It incorporates a published study which examined the support context for patients using CSII therapy from the healthcare professional perspective, and contextual influences for healthcare professionals and their patients in the Hunter New England Local Health District of New South Wales. Interview data for this chapter originated from the YOuR-Diabetes program.

Perry. L, James. S, Gallagher. R, Dunbabin. J, Steinbeck. K, Lowe. J (2017). Supporting patients with type 1 diabetes using continuous subcutaneous insulin infusion therapy: difficulties, disconnections and disarray.
Journal of Evaluation in Clinical Practice. 21st February (Epub ahead of print).

The paper is appended at Appendix 9.

Journal choice rationale

The rationale for choice of the Journal of Evaluation in Clinical Practice was set out in chapter 4.

Paper 4

Aims

This study aimed to examine from the healthcare professional perspective the support context for patients using CSII therapy, as well as contextual influences for healthcare professionals and their patients.

Methods

This qualitative study was undertaken using an ethnographic research design in partnership with Hunter New England Local Health District (chapters 3 and 4) [237, 238]. Participants were eligible for the study if they were healthcare professionals with current or recent responsibility for providing care for people with type 1 diabetes using CSII therapy.

Ethical approvals for the study were obtained from Hunter New England (HREC 07/09/19/4.01) and University of Newcastle (H-634-1107) (Appendix 6) Human Research Ethics Committees.

Recruitment occurred using a snowball sampling technique, as there was no list of eligible diabetes healthcare professionals in Hunter New England Local Health District. Sampling began with members of an established Hunter New England Local Health District-wide diabetes service group. All contacts were asked to voluntarily identify healthcare professionals they were aware of with current or previous experience with CSII therapy, regardless of whether they themselves decided to participate or not. The process was repeated until there was broad representation across healthcare professional

groups and geographical locations, and it was felt data saturation had been achieved. At first contact, potential participants were supplied with a letter of introduction, study information and a consent form.

Data were collected using individual semi-structured interviews undertaken by an experienced female clinical researcher (a Registered Nurse and Credentialled Diabetes Educator) by telephone during 2011 - 2012. Telephone interviews were chosen to facilitate participation by rural and regional healthcare professionals and provide privacy for sharing potentially sensitive information or opinions. The interview schedule (Appendix 10) was developed during discussion by research team members, reviewed by clinicians from another health district, piloted and provided to consenting participants ahead of the telephone interviews. Participants were also asked to briefly describe their geographical location, professional background and, depending upon their employment, either their personal or service caseload of CSII users. Each interview commenced with an introduction and explanation of confidentiality principles. All interviews were audio recorded and brief field notes collected.

Audio data and interview field notes were transcribed and imported into NVivo^{TM} 10 software. All data were de-identified. Data analysis was guided by Gibb's [294] framework and organised thematically. The framework included transcription and familiarisation, code building, theme development, data consolidation and interpretation. Transcripts were read by the first three authors with coding initiated by the second author. This was followed by emergent coding and organisation of themes, developed during discussion with all authors to reach consensus. Multiple investigators for the analysis allowed development of complementary and divergent understandings,

and provided a context in which beliefs, values, perspectives and assumptions could be revealed and contested. Transcripts were not returned to participants though local presentation of findings provided opportunities to comment.

Results

Twenty-seven semi-structured telephone interviews were conducted with a variety of healthcare professionals working at diverse sites across metropolitan (n = 15), regional and rural areas (n = 12); one non-metropolitan interview was inaudible. Interviews analysed lasted mean (SD) 30 (14.4) minutes and participants identified themselves as diabetes nurse educators (n = 12, one also a health service manager), dietitians (n = 3), endocrinologists (n = 5, 3 paediatric and 2 adult), paediatricians (n = 3) and general practitioners (n = 3). The paediatric CSII caseloads of healthcare professionals ranged from one to one-hundred and fifty; those of adult healthcare professionals ranged from two to sixty-five patients.

An overarching theme of difficulties, disconnections and disarray emerged from the data. Difficulties occurred partly as a result of the availability and range of appropriate CSII expertise, which was perceived to exert a pervasive effect. This was in addition to barriers to access to CSII devices, consequent to government and private health insurance policy conditions. A lack of shared access to documentation and communication between adult and paediatric services, between separate components of the health service and with healthcare professionals across organisations, resulted in disconnections which hindered a consistent, coordinated and informed approach to care. Finally, disarray followed the absence of consensus or definition for some key

organisational processes and the subsequent delivery of care that was sometimes not standardised or consistent. There was also no consensus or policy for the specific training processes required by healthcare professionals to provide CSII-related care.

Shortages of healthcare professional expertise

Participants (particularly those working in non-metropolitan locations) expressed frustration with the lack of specific healthcare professional expertise available for their patients, which they considered essential to support CSII use:

> *"Because we have no endocrinologist up here …. in effect, there is really no service for young adults here on insulin pump therapy."* (healthcare professional 26: non-metropolitan)

However, there was no consensus or policy for the specific training processes required by healthcare professionals to provide CSII-related care. Competence was often obtained serendipitously and in many cases was funded by the individuals themselves or provided by diverse CSII manufacturers. This unsystematic approach to education may have contributed to the inconsistent support for CSII use. The availability and range of appropriate CSII expertise was perceived to exert a pervasive effect, including determination of whether CSII use was initiated or even raised as an option with a patient. Even more problematic, some health providers were reported as declining to engage in discussion or management of diabetes with current CSII users. As one paediatric endocrinologist stated:

"The system doesn't allow for initiating or monitoring children or adolescents, or young adults on pumps here anyway." (healthcare professional 12: non-metropolitan)

This apparent failure of the system to acknowledge and engage with this care need occurred across the continuum of care, including while the patient was admitted to hospital, unwell and in need of support. This was most commonly reported in non-metropolitan areas.

The consequences of the lack of CSII expertise were far-reaching: those experts that were available had limited time, so extra efforts had to be made by non-expert staff to maximise the experts' time to address patients' issues. This could occur in metropolitan areas as well, as explained by a diabetes nurse educator:

"It's a real effort trying to contact support doctors because we don't have any on site. The only time we have people on site is for the …. clinic so if I've got any issues that are burning I'll confront them …. at the clinic." (healthcare professional 04: metropolitan)

The lack of expertise in hospital settings also meant that expert staff (predominantly the diabetes nurse educators) reported commonly going above and beyond their work requirements by providing personal telephone numbers to patients and their immediate families. However, the processes applied in identifying who required this extra support and for whom the healthcare professionals were willing to disrupt their home life were

unclear, but it was obvious that some degree of personal risk was perceived by participants:

> *"It sort of sounds bad but it depends on the client …. I always give my home number and my mobile number if they need it, but I might be a bit careful with some people about giving that out if I think that it's going to backfire on me."* (healthcare professional 16: non-metropolitan)

Despite this, few of the more expert participants expressed concern about their colleagues' difficulties. Only one interviewee (a diabetes nurse educator) raised other healthcare professionals' needs or expressed a sense of responsibility to support those in non-metropolitan settings:

> *"I think we should have maybe a few meetings where the issues with insulin pump therapy …. what the guys out in the country need."* (healthcare professional 20: metropolitan)

Service structure and process shortfalls

The lack of shared access to documentation and communication between adult and paediatric services, between separate components of the health service and with healthcare professionals across organisations hindered a coordinated approach to care. Where patients had been lost to follow-up, participants (predominantly physicians) reported being unaware whether patients had connected with a diabetes service in another location. The assessments and plans activated by one professional could be largely unknown to another, resulting in patients repeating their history and providers

duplicating efforts. One general practitioner emphasised his frustration at not having reciprocal access to the records of the local hospital, children's hospital or community health:

> "*They* [healthcare records] *all seem to be in three separate places, so they* [healthcare professionals] *all have to take another full history and go through it all."* (healthcare professional 27: non-metropolitan)

Lack of access to records meant that specialists could be asked to make recommendations based on very little information. For example, this endocrinologist expressed discomfort at signing approvals to commence CSII therapy:

> *"A lot of patients come into clinic as a one off .... use me as a one off specialist to sign them off for the pump, which I'm not really happy about. They* [the patients] *have never seen me before .... I don't know what level of knowledge and skills they have."* (healthcare professional 21: metropolitan)

Another deficit was the absence of consensus or definition for some key organisational processes. Subsequently, care provided was not standardised with potential for advice to CSII users to vary for initiation, maintenance and support of this technology when considering aspects such as patient selection, expertise provided and follow-up, depending on the location and individual healthcare professionals they attended. 'Hit and miss' processes potentially resulted in inconsistent patient follow-up:

"*At the moment, there's no recognised program in place. It's all hit and miss …. There's a real risk, in the current setup, that we put people on pumps, we see them perhaps a couple of times afterwards and then they sort of disappear into the wilderness."* (healthcare professional 29: metropolitan)

CSII device access

The ability of patients to commence CSII therapy or update their CSII device was ultimately influenced by access to funding. Individuals who did not have private health insurance or personal resources often could not afford initial set-up costs. Some CSII users had the device provided in childhood through a government subsidy but had difficulties as they transitioned from childhood because the subsidy ceased and, starting their working lives, their financial circumstances prohibited purchase. This sometimes meant low income young adults continuing to use their CSII device beyond the life and optimal function of the equipment. Participants had no option but to continue providing support in this situation, even if it was not what they saw as the patient's best interest:

"The pump itself is faulty because it's very old and at the moment she [the patient] *doesn't have the resources to acquire another pump."* (healthcare professional 26: non-metropolitan).

Private health insurance providers' requirements for funding CSII devices influenced service delivery. All private health insurance funds required a physician specialising in diabetes to sign an approval to commence CSII therapy; many also required a hospital admission at the time of commencement. Many participants (particularly rural staff) viewed this requirement as useful both socially and economically because of the

distances some patients would have to travel, in the event of technical, operational or related medical problems. Others (particularly metropolitan staff), however, saw this in a more negative light, considering the disruption to patients' lives and costs to the public healthcare system irrespective of clinical need. Some participants navigated around this requirement by creating virtual wards so patients were not physically admitted, thereby reducing the impact of an admission on their patients and the wider public health system.

Collectively, from healthcare professionals' perspectives, issues illustrated difficulties, disconnections and disarray in the support for patients using CSII, and how this context functions for healthcare professionals and their patients. Inequities and uncoordinated healthcare were described. This reflected lack of specific expertise in some locations but also lack of teamwork and common agreed care policies and processes, all undermined by lack of common data systems, communication infrastructure and connectivity. This left unsupported individuals unwilling to contribute to CSII care, and forced others to decide for themselves which patients received what forms of support.

Healthcare professionals perceived benefits and shortfalls accruing to government and private health insurance policy conditions. Government policy recognised the importance of supporting equity of access for disadvantaged children. However, eligibility for the CSII device subsidy ceased at age 18 years, whereas the economic disadvantage could persist beyond this. Private health insurers requiring a hospital admission for CSII commencement irrespective of clinical need potentially benefited some patients but unnecessarily burdened others and the public healthcare system, causing further difficulties and disarray.

Discussion

This study provides insights into healthcare professionals' perspectives of the complexity of providing support for patients using CSII therapy across diverse contexts, and lays out a platform for further research and service innovation. Previous local and international research focusing on service support for type 1 diabetes, and chronic disease in general, have also demonstrated deficiencies in planning and provision of specialist healthcare professional expertise and management [41, 69, 254, 295]. This group of healthcare professionals indicated that these were live issues not just for patients but for their healthcare providers.

CSII users need ongoing support and monitoring, and their healthcare teams need to be able to deliver this, to provide the best chance to delay or deter the development of vascular complications that are seen in people with type 1 diabetes at young ages (chapters 2 and 3), and their associated costs [29-32]. Economic analysis under research conditions has demonstrated the benefit of CSII versus multiple daily injections [296]. What is needed now is to put into daily clinical practice those elements that are required to translate the benefits seen in research into 'business as usual' clinical practice. The findings of this study flag important deficits that may need attention, for this to occur.

Ways to promote and support engagement, both for patients and healthcare professionals, should be considered [297]. Eligibility criteria for a CSII device subsidy from the Australian Government includes the stated presence of a system to ensure follow-up and ongoing support [149]. However, there are no in-built facilitators, inducements or monitoring to ensure that this is honoured. Further, outside of National Diabetes Services Scheme registration requirements there are no in-built facilitators or

inducements to promote regular engagement of CSII users with diabetes health-care teams; in this study the risk of patients being lost to CSII-related follow-up was highlighted. This flags, at minimum, the need for integration of healthcare records on a mandatory rather than voluntary basis, with pan-Australian access accorded to healthcare providers across primary to tertiary services. Financial incentives to maintain contact with health services such as those in Ontario, Canada, could also be considered [298].

Many staff (predominantly in metropolitan areas) expressed the need for improved and perhaps dedicated services for CSII users. This strategy could support development of a structured team approach, potentially enabling more consistent patient follow-up and perhaps better patient outcomes from CSII usage. A place to start might be in the dissemination and adoption of Australian evidence-based CSII therapy clinical guidelines [97]. Policies and procedures to translate guidelines into practice should be formulated. These should consider the appropriate selection of patients for CSII use and self-management, as well as the expertise required by healthcare professionals to care for CSII users and support other staff [96-98]; to enable professional development of competent healthcare professionals to support CSII-related care. Australian state-based guidelines for in-hospital CSII care are available [299].

To augment the dedicated services suggested above, phone, online and electronic support can be considered, particularly for young adults [254] and staff in regional, rural or remote areas. Technologies such as video-conferencing may also benefit and facilitate the provision of peer support amongst diabetes healthcare professionals, and healthcare professional support for patients where this is otherwise locally lacking

[175]. Whether CSII is the best option for a patient needs to be carefully considered, including at the time of transition, also taking account of ongoing access to appropriate supportive care.

Findings also suggest that policy innovation may also be required to enable equitable CSII access. Australian Government funding for access to a CSII device, supportive of children, could potentially be extended to cover the early adult years of eligible young people with type 1 diabetes [297]. Aspects such as device and consumable provision, upgrades and the technology support required to achieve the anticipated benefits for the entire period of CSII therapy use should be further investigated. Given the complex nature of patterns of socio-economic advantage and disadvantage amongst the community, it is possible that increased financial support alone might exacerbate rather than ameliorate inequalities between those who can afford to use CSII and those who cannot.

The representative nature of the sample from which findings derived is impossible to gauge. Nonetheless the sample comprised a large proportion of healthcare providers covering a very large geographical area. The use of snowball sampling may have generated sampling bias due to initial participants nominating healthcare professionals they knew, who may have shared opinions as well as experiences, and whose recruitment was by self-selection. These healthcare professionals were employed by a single public healthcare provider, albeit participants worked as members of multiple different local teams. Findings reflect their experiences and perceptions at one point in time.

Conclusions

Findings clearly indicate the need for policy and practice innovation to better enable staff to support patients with type 1 diabetes using CSII therapy, and to support staff providing this care, especially in non-metropolitan areas. The need for consistent and coordinated care, and the infrastructure to facilitate this, drives an opportunity to reconfigure relationships between acute centres (often the repositories of specialist expertise) and community/primary care, where such expertise is required for preventive care but often lacking. It presents an opportunity to drive integration of care, and team-working, across as well as within disciplines and settings.

Comprehensive service and education planning and monitoring involving diabetes healthcare professionals nationwide may be required; in many geographical areas, appropriate resource allocation and use of other technologies to promote engagement with and between diabetes services may be warranted to demonstrate the comparative cost effectiveness of service redesign. Diabetes technology is advancing rapidly, requiring a skilled and responsive workforce and flexible health services capable of adapting rapidly to change. The need for service innovation and redesign is pressing.

Summary

Findings from these interviews with healthcare professionals (n = 26) identified the complexity of providing support for patients using CSII therapy. They highlight the gaps between young people's expectations (chapter 4) and healthcare professionals' expectations and the capacities and realities of service delivery.

An overarching theme of difficulties, disconnections and disarray was identified. Difficulties occurred partly as a result of the availability and range of appropriate CSII expertise, in addition to barriers to access to CSII devices. A lack of shared access to documentation and communication between adult and paediatric services, between separate components of the health service and with healthcare professionals across organisations, hindered a consistent, coordinated and informed approach to care. Finally, disarray followed the absence of consensus or definition for some key organisational processes and the subsequent delivery of care that was sometimes neither standardised nor consistent.

Collectively, findings provide insights from healthcare professionals' perspectives into the complexity of providing support for patients using CSII across diverse contexts, and provide a platform for further research. The need for consistent and coordinated care, and the infrastructure to facilitate this, flags an opportunity to drive integration of care and team-working across as well as within settings and disciplines.

CHAPTER 6. DIABETES EDUCATORS' INTENDED AND REPORTED USE OF COMMON DIABETES-RELATED TECHNOLOGIES

Study rationale

Technology is providing new opportunities to deliver care and promote disease management, communication and engagement with healthcare services. However, technology use by health consumers often requires the support of specialist expertise. The previous paper took a 'team' approach in exploring healthcare professionals' experiences and perceptions of supporting CSII use; whilst dominant in this area, CSII is not the only form of diabetes-related technology in use.

Diabetes educators, healthcare professionals predominantly from the disciplines of nursing and dietetics, are key to the education, treatment and support of people with type 1 diabetes and ideally placed to promote and support appropriate technology use. Few studies have examined diabetes educators' use of diabetes-related technologies for patients with type 1 diabetes (chapter 5), and none have examined their intentions; information needed for comprehensive service and education planning. This chapter addresses this limitation, providing information to support future strategy development. It incorporates the first published study of the intended and reported professional use, and factors predictive of use, of common diabetes-related technologies by diabetes educators across Australia, for patients with type 1 diabetes. This study includes an adapted and validated version of a survey instrument based on the Technology Acceptance Model (TAM) [300-305], suitable for exploration of technology use in healthcare environments.

James. S, Perry. L, Gallagher. R and Lowe. J (2016).

Diabetes Educators' Intended and Reported Use of Common Diabetes-Related Technologies: Discrepancies and Dissonance.

Journal of Diabetes Science and Technology, 10:6, 1277 - 1286.

The paper is appended at Appendix 11.

Journal choice rationale

The Journal of Diabetes Science and Technology publishes research across all fields of diabetes technologies, on a bi-monthly basis. The authorship team considered the journal to be suitable based upon its journal quality, and article promotion and visibility policies (Table 12).

Table 12: Journal of Diabetes Science and Technology

Criteria	Why suitable
Journal quality	The Journal of Diabetes Science and Technology is a high profile, universally respected diabetes and technology publication. Rigorous peer review is maintained and the journal has an impact factor of 1.78 (2015)
Article promotion and visibility	Final revision articles are hosted online prior to their inclusion in a final print and online journal issue. Published articles are made available, free of charge, after one year. Articles are included in periodic email article alerts and updates, and are indexed in a wide range of electronic databases (Index Medicus/MEDLINE; PubMed; and PubMed Central)

Paper 5

Aims

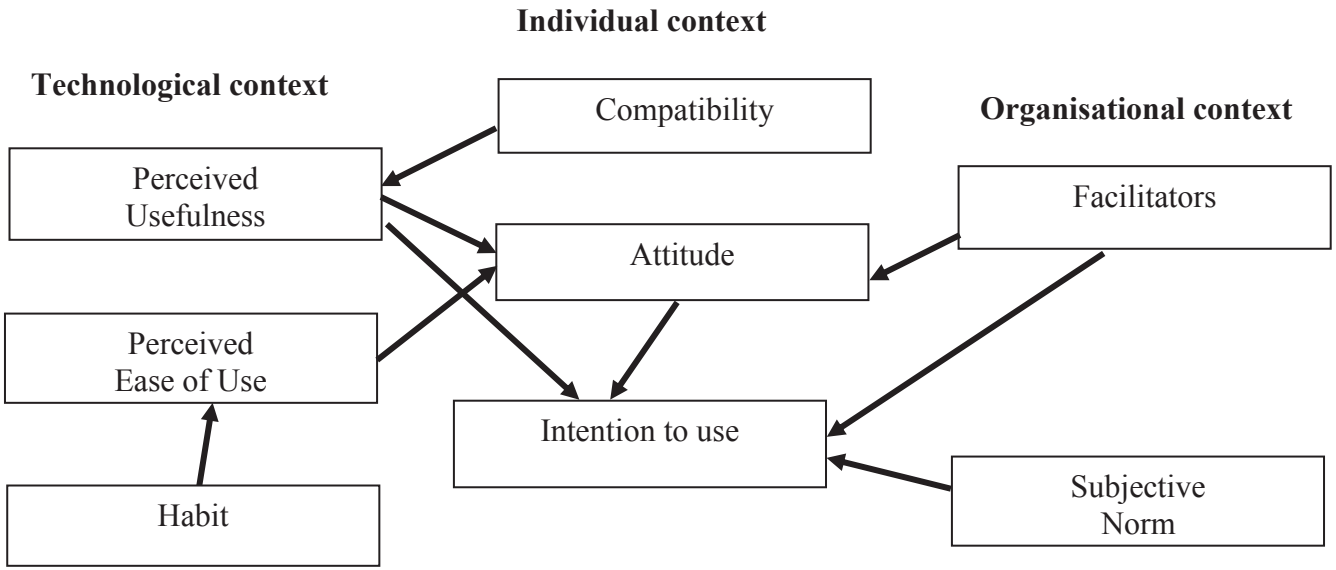
This study aimed to determine diabetes educators' intended and reported professional use of common diabetes-related technologies for patients with type 1 diabetes, and predictive factors.

Methods

Theoretical framework

The main theoretical framework underpinning the study was the TAM, an information systems theory that models how users come to accept and use a technology [300, 301, 303-305]. Originally developed to examine responses to computer technology, the model has been revised for translation to the healthcare context and used to examine, first, telemedicine technology acceptance by physicians [306] and then evaluation of home telemonitoring for patients with heart failure and/or chronic obstructive pulmonary disease [302]. Factors were added from relevant theories, mapping influences on behavioural intention from individual, technological and organisational contexts (Figure 3).

Figure 3: Proposed theoretical framework for technology acceptance



This framework was proposed by Gagnon et al. [302]

Design and data collection

A survey design was used and data were collected with an anonymous, web-based questionnaire.

The Technology Acceptance Model (TAM) instrument

The most recent TAM model used in healthcare prior to this study included habit, facilitating conditions and subjective norms but omitted peer influence and perceived technology control (ability or competence) [302]. No rationale was supplied for these changes, yet perceived technology control may be important as shortages of healthcare professional expertise was a reason why healthcare professionals did not engage with CSII-related care (chapter 5). This 33-item version of the questionnaire [302] had four questions on attitude (perceived positive or negative consequences of adopting the technology) and compatibility (the degree of correspondence between a new technology and existing values, past experiences and needs of potential adopters) in the individual context. Within the technological context, six questions sought perceived ease-of-use and usefulness, and three focused on habit (behaviour that has become automatic). Within the organisational context four questions related to subjective norms (the extent to which an individual believes that people who are important to them will approve of their behaviour adoption), and three to facilitating conditions (the degree to which individuals believe that organisational and technical infrastructures support usage). Three questions on intention were included. Responses were measured on a seven point Likert scale from -3 = Totally disagree to 3 = Totally agree, with scores summed for each of the eight factors. Validity was supported by a panel of experts in technology, and Cronbach alpha values greater than or equal to 0.7 were reported for all but one factor (habit = 0.56). This version of the model had not been formally tested.

Customising the instrument for this study

For this study modifications to the questionnaire included wording changes to relate to type 1 diabetes, and removal of negative values from the Likert scale for more intuitive scaling (from 1 = Strongly disagree to 7 = Strongly agree). Seven questions were added: one question determined technology use and frequency measured on a five point Likert scale (1 = Never, 2 = Daily, 3 = Weekly, 4 = Monthly and 5 = Occasionally), and six questions related to competence in provision of information and advice, data interpretation, operation, problem solving and overall competence for these technologies (measured using the original scale of 1 = Strongly disagree to 7 = Strongly agree). Finally, an extra response choice of either 'Already know', 'Already use' or 'Intend to continue' was added to six questions, to distinguish existing knowledge and technology usage.

The questionnaire was formatted to ask participants to consider the four technologies separately, and questions were added to collect data to characterise participants' age, sex, healthcare qualifications and experience. The modified questionnaire was reviewed for face and content validity by two subject matter experts, both physicians with extensive research and diabetes experience, and piloted by eight Canadian-based diabetes educators; minor changes were made for ease of moving through the survey (Appendix 12).

Exploratory factor analyses using an iterated principal axis analysis with promax rotation examined the factor structure for each of the four technologies separately. Discriminant validity was evaluated by inspecting the construct loadings of each factor,

applying criteria of a primary factor loading of 0.4 or above and no cross-loading of 0.6 or more [307]. Initial factor analyses identified that nine questions did not consistently load on identified factors for three or more of the technologies. Their exclusion resulted in a replicating five factor solution and improved fit across the four technologies. These five factors were: confidence and competence, improving clinical practice, preparation (intentions and training), ease of use and subjective norms. For the questions related to CSII, these factors explained 71.17% of the variance, 70.13% for CGM, 71.09% for apps and 67.95% for video-conferencing. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.934 or above, and Bartlett's tests of sphericity were significant (CSII = X^2 6798, $p < 0.001$; CGM = X^2 6485, $p < 0.001$; apps = X^2 6500, $p < 0.001$; and video-conferencing = X^2 5813, $p < 0.001$). The diagonals of the anti-image correlation matrix were all 0.86 or above and, excluding one question relating to CSII, CGM and apps, communalities were all 0.4 or above.

Finally, Cronbach's alpha values were acceptable for all factors for all technologies. For the confidence and competence factor, values ranged from 0.95 - 0.974, for improving clinical practice, from 0.914 - 0.935, and the other domains ranged from 0.756 - 0.927. Items pertaining to competence in the 'confidence and competence' factor were highly correlated (CSII = 0.614 - 0.953; CGM = 0.646 - 0. 944; apps = 0.662 - 0.929; and video-conferencing = 0.481 - 0.915); however, the explanatory power of the factor was not improved by removal of any combination of these items (Table 13).

Table 13: Factor structure

Factor	Question	Original factor
Confidence and competence	-Use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) would necessitate major changes in my clinical practice:	Compatibility
	-I feel comfortable with the following diabetes-related technologies:	Habit
	-I already use the following diabetes-related technologies (where suitable) in the management of patients with type 1 diabetes:	Habit
	-I often use the following diabetes-related technologies in my work:	Habit
	-I am competent overall with the following diabetes-related technologies:	
	-I am competent providing information about the following diabetes-related technologies	
	-I am competent interpreting data obtained from the following diabetes-related technologies:	
	-I am competent providing advice to patients about the following diabetes-related technologies:	
	-I am competent operating the following diabetes-related technologies:	
	-I am competent problem-solving with the following diabetes-related technologies:	
Improving clinical practice	-I think it is a good idea to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable):	Attitude
	-Use of the following diabetes-related technologies may be/are beneficial for the care of my patients with type 1 diabetes (where suitable):	Attitude
	-In my opinion, use of the following diabetes-related technologies in the care of my patients with type 1	Attitude

	diabetes (where suitable) will have/has a positive impact:	
	-Use of the following diabetes-related technologies may promote good clinical practice:	Compatibility
	-Use of the following diabetes-related technologies (where suitable) may improve management of my patients with type 1 diabetes:	Usefulness
	-The following diabetes-related technologies can improve my performance in care of my patients with type 1 diabetes (where suitable):	Usefulness
	-The following diabetes-related technologies can facilitate the care of my patients with type 1 diabetes (where suitable):	Usefulness
	-In general, the following diabetes-related technologies may be useful/are useful to improve the care of my patients with type 1 diabetes (where suitable):	Usefulness
Preparation (intentions and training)	-I would use the following diabetes-related technologies if I receive appropriate training:	Facilitating conditions
	-I would use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) if I receive the necessary technical assistance:	Facilitating conditions
	-I intend to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) when they are available at my centre:	Intention
	-I intend to use the following diabetes-related technologies when necessary to provide healthcare to my patients with type 1 diabetes:	Intention
	-I intend to use the following diabetes-related technologies routinely for the care of my patients with type 1 diabetes (where suitable):	Intention

Ease of use	-I think it would be/is easy to perform the tasks necessary to manage my patients with type 1 diabetes using the following diabetes-related technologies (where suitable): -I believe that the following diabetes-related technologies will be/are clear and easy to understand: -I think I will find it easy/I found it easy to acquire the skills necessary to use the following diabetes-related technologies: -I think that the following diabetes-related technologies will be/are easy to use:	Ease of use Ease of use Ease of use Ease of use
Subjective norms	-Most of my patients with type 1 diabetes welcome/would welcome me using the following diabetes-related technologies: -Health Managers would welcome/welcome me using the following diabetes-related technologies: -Other health professionals (nurses, other specialist etc.) would welcome/welcome me using the following diabetes-related technologies:	Subjective norms Subjective norms Subjective norms

Sample

A convenience sample was collected from members of the Australian Diabetes Educators Association; the leading Australian organisation for multidisciplinary healthcare professionals who provide diabetes education and care. This organisation had 1,747 members at 30th June 2013 [308]. To be eligible, participants were required to have experience as a diabetes educator in Australia, current membership with the Australian Diabetes Educators Association, and be registered to receive the Australian Diabetes Educators Association's electronic newsletter; numbers of eligible members were not known.

Ethical approval for the study was obtained from the University of Technology Sydney Human Research Ethics Committee (UTS HREC 2014000287, 4th June 2014 (Appendix 13), and UTS HREC 20140005 (a variation)).

Procedure

The web based survey was undertaken June - August 2014. Potential participants were advised of the study and could access it through a link in the Australian Diabetes Educators Association weekly electronic newsletter, operational for 12 weeks to allow for response patterns previously experienced in this population (Appendix 14) [309]. Reminders were posted in the newsletter at two, four, six, eight and ten weeks following the first advice of the survey. Through the use of the skip logic feature in SurveyMonkey®, respondents were only asked relevant questions based on their previous responses. A total of 247 questionnaires were partially or fully completed; 19 provided only demographic data and were omitted from data analyses.

Data analyses

Data were entered into SPSS© version 23 software. Area of employment was categorised [282], and for each of the four technologies, responses for reported technology use were categorised (no/yes) and compared with socio-demographic data using the Chi-square test, where theoretical or clinical reasons identified these characteristics as potential influences [310, 311]. Questions were otherwise analysed as ordinal measures and summed for each of the five factors, and for the three questions relating to intentions; two questions required reverse-coding. Frequencies and medians (25, 75 quartile) scores, where appropriate, were used descriptively.

Logistic regression analyses were undertaken to identify independent predictors of diabetes educators' intentions and reported use of the four technologies. Dependent variables were intention to use each technology summary scores dichotomised at median scores into low and high intention (due to non-normal distribution), and reported use (no/yes). Potential predictor variables comprised summary scores of the five factors identified through the factor analyses (though the single item factor 'preparation (intentions and training)' was not considered for analyses as a potential predictor of technology intention) and socio-demographic data. The backward entry method was selected to create the most parsimonious model and adjusted odds ratios and 95% confidence intervals reported. All assumptions of the models were tested and met. A p value of less than 0.05 was considered significant.

Results

The majority of respondents' (n = 228) were female nurses, although multiple disciplines were represented (Table 14). Respondents had many years' experience in both their professions and in diabetes education, and were well educated. Most were presently credentialled with the Australian Diabetes Educators Association and had experience working with paediatric and/or young adult patients with type 1 diabetes; of those with experience working with paediatric patients with type 1 diabetes, almost all (n = 125, 99.2%) also had experience with young adults with type 1 diabetes. Most (91.7%) were currently working in Australia and in cities, with all states and territories of Australia represented.

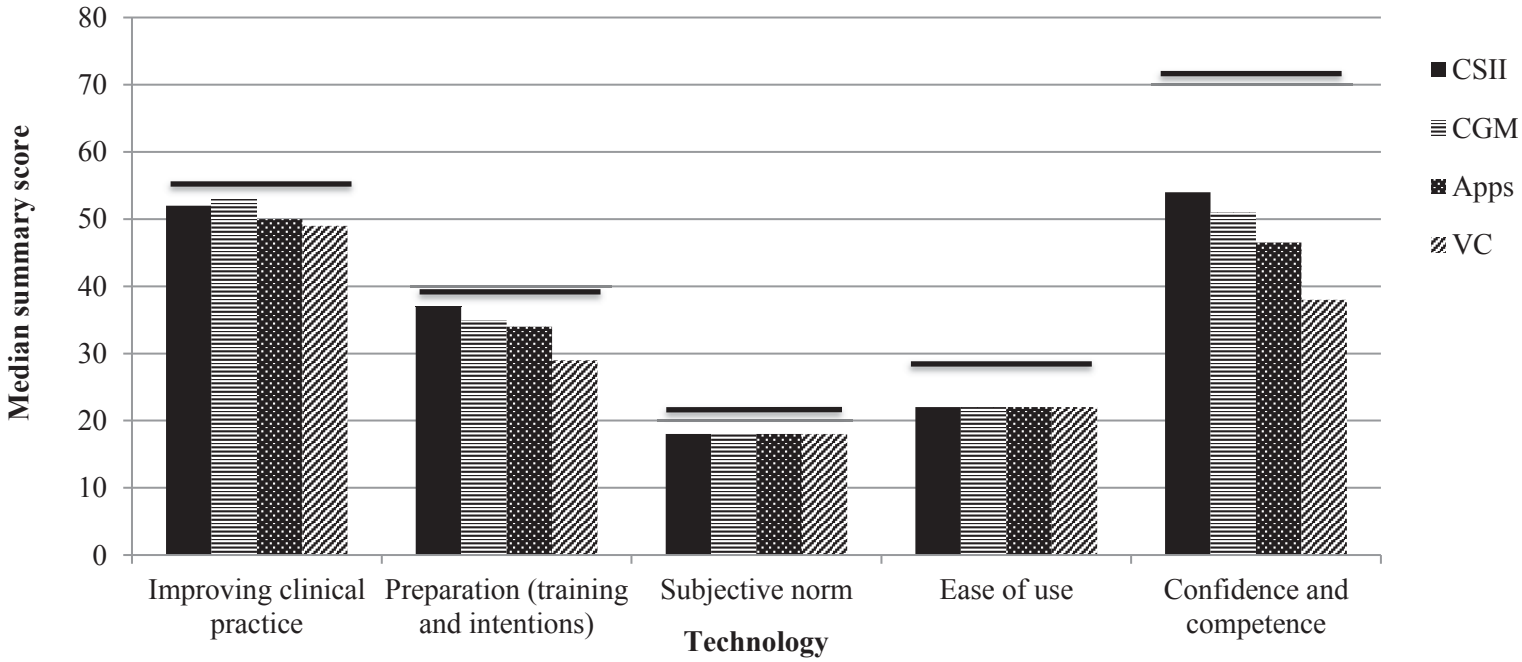
Summary scores of the five factors identified from the questionnaire as potentially influential for technology adoption were relatively consistent across the four technologies (Figure 4). Highest scores indicated that respondents strongly perceived positive consequences for patient care of adopting the four technologies; the lowest scores were for respondents' reported confidence and competence. With maximum possible scores of seven (1 = Strongly disagree to 7 = Strongly agree), overall respondents reported they felt competent with CSII (median (25, 75 quartile) score 6 (3, 7)), and somewhat competent with CGM (5 (3, 7)) and apps (5 (3, 6)). However, they neither agreed nor disagreed they were competent with video-conferencing (4 (2, 5)). They reported at least some degree of competence with each facet identified (Figure 5).

Table 14: Respondent characteristics

Characteristic [n 2 28 unless stated]	**n (%)** [unless stated]
Age (years), mean (SD, min - max)	47 (10, 24 - 66)
Experience (years), median (25, 75 [min - max]) -	
In their profession	20 (10.5, 30 [1 - 48])
In diabetes education	8 (4, 14 [1 - 40])
Male gender	26 (11.4)
Profession -	
Nurse	209 (91.7)
Dietitian	16 (7)
Other	3 (1.3)
Highest professional qualification -	
Masters	43 (18.9)
Diploma	66 (28.9)
Bachelor's +/- honours degree	119 (52.2)
Presently credentialled with the ADEA (Yes)	167 (73.2)
Young adult experience^ (Yes)	209 (95.4)
Paediatric experience^ (Yes)	126 (57.5)
Area of employment [n = 203] -	
Major city	141 (69.5)
Inner regional	42 (20.7)
Outer regional	15 (7.4)
Rural and remote	5 (2.5)

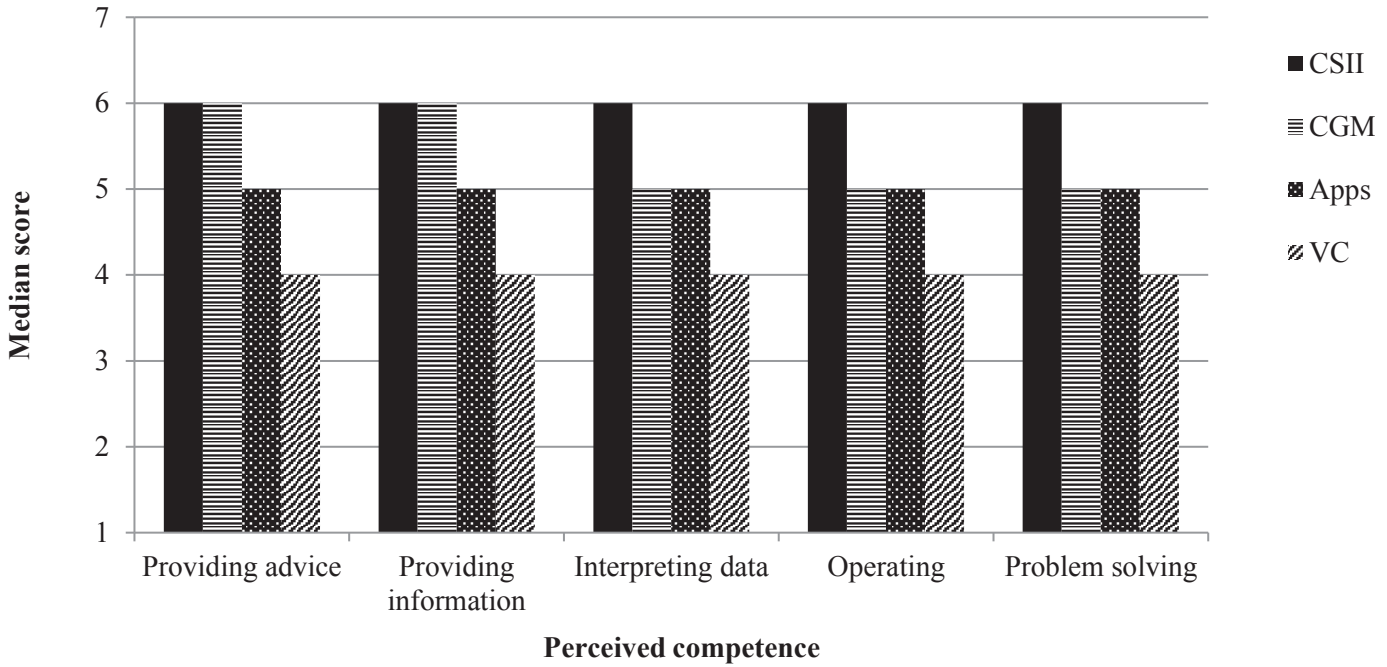
n = Number. Min = Minimum. Max = Maximum.
ADEA = Australian Diabetes Educators Association.
^Working with respective patients with type 1 diabetes.

Figure 4: Factors influencing diabetes educators' reported use of common diabetes-related technologies for patients with type 1 diabetes



CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications. VC = Video-conferencing.
A higher median summary score indicates greater agreement.
Maximum possible scores (indicated): Improving clinical practice = 56. Preparation (training and intentions) = 39.
Subjective norm = 21. Ease of use = 28. Confidence and competence = 71.

Figure 5: Diabetes educators' reported competence in use of common diabetes-related technologies for patients with type 1 diabetes

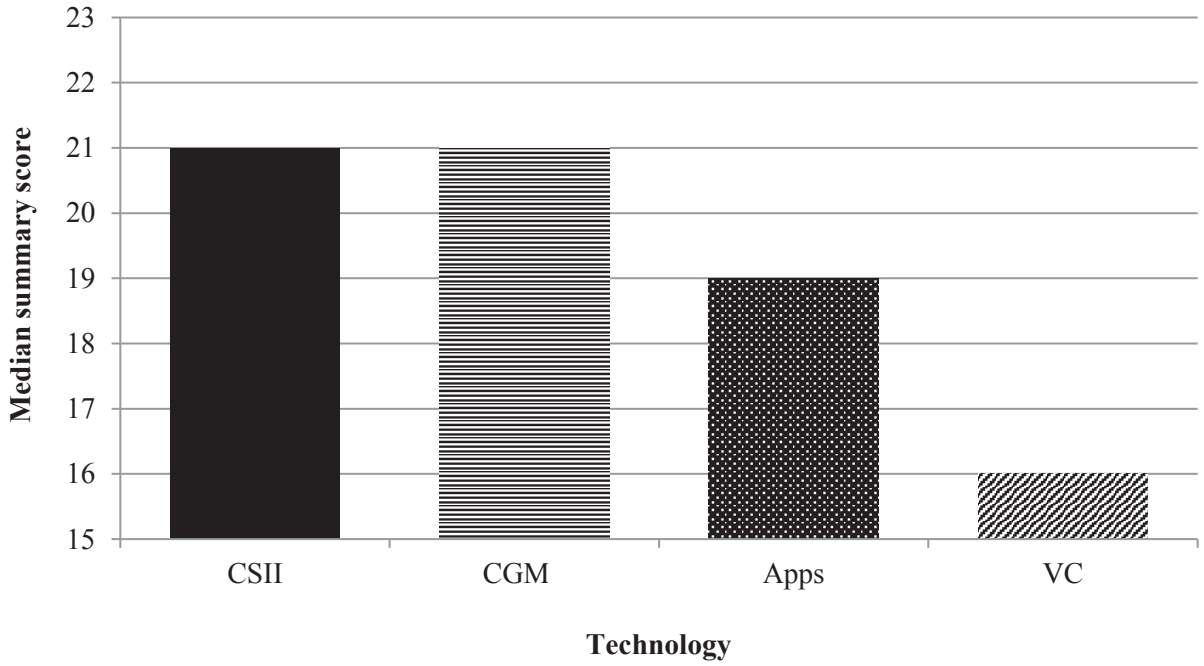


CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications. VC = Video-conferencing.
Rated 1 = 'Strongly disagree' to 7 = 'Strongly agree'.

Respondents had strongly positive intentions to use common diabetes-related technologies for patients with type 1 diabetes, particularly CSII and CGM; somewhat less so for apps and video-conferencing (Figure 6). The majority of respondents also reported using CSII, CGM and apps for patients with type 1 diabetes. Around four of every five respondents reported using CSII (80.3%), around two in three used CGM (65.4%) or apps (69.7%), but only around one in three used video-conferencing (36.4%). Significantly greater proportions of those with, rather than lacking, experience working with paediatric patients with type 1 diabetes reported using CGM, apps or video-conferencing. A greater proportion of diabetes educators employed outside of major cities reported using video-conferencing. Overall, where these technologies were used, this was on an 'occasional' basis.

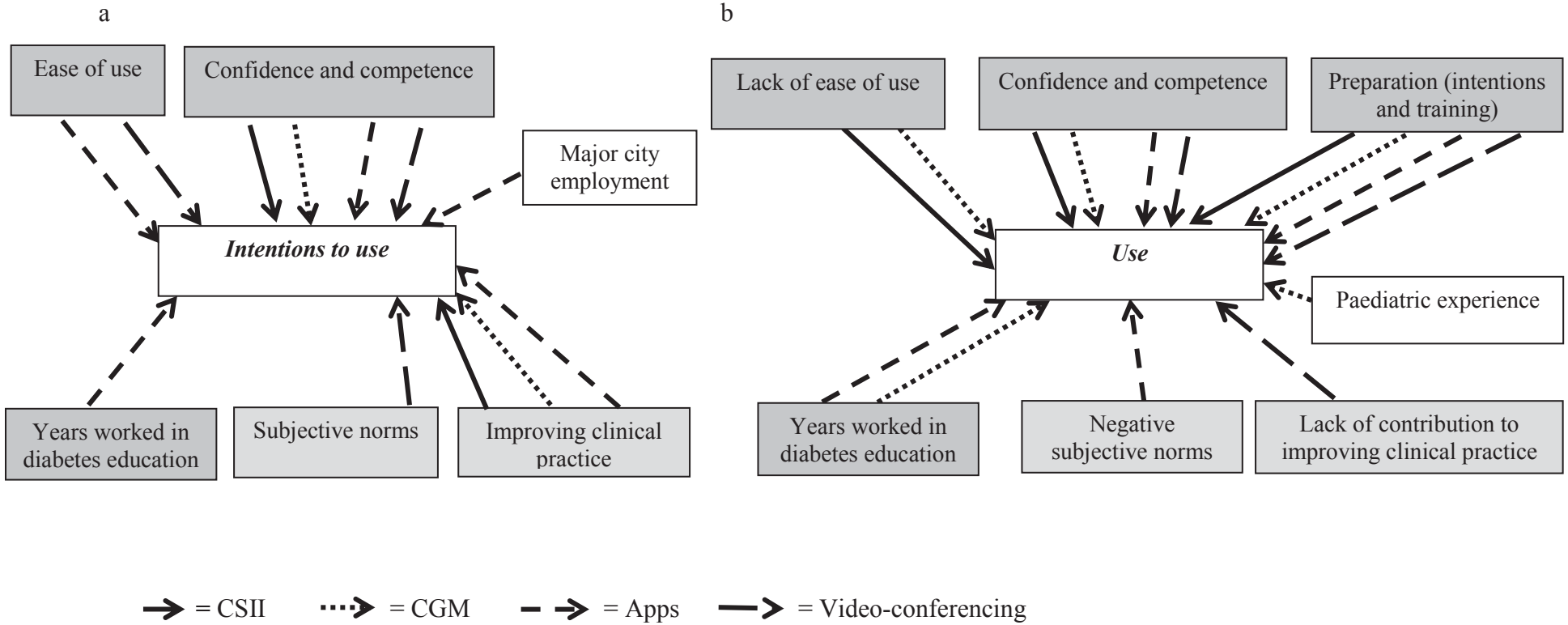
Many predictors of both intended and reported actual use of common diabetes-related technologies exhibited substantial effects across the technologies. Confidence and competence consistently positively predicted diabetes educators' intentions to use each of the four technologies. Ease of use was also predictive of intention to use apps and video-conferencing; years worked in diabetes education positively predicted intention to use apps (Figure 7a; Table 15). Subjective norms were also important, positively predicting diabetes educators' intentions to use video-conferencing; perceived improvement to clinical practice consistently and positively predicted diabetes educators' intention to use all technology except video-conferencing. Employment in a major city was predictive of diabetes educators' intentions to use apps.

Figure 6: Diabetes educators' intentions to use of common diabetes-related technologies for patients with type 1 diabetes



CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications. VC = Video-conferencing.
A higher median summary score indicates greater intention. Maximum possible score = 23.

Figure 7: Common diabetes-related technologies - influences on diabetes educators' intentions and reported use



CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications.

Table 15: Independent predictors of diabetes educators' intentions to use common diabetes-related technologies for patients with type 1 diabetes

Dependent / **Independent**	**CSII** OR (95% CI)	p value	**CGM** OR (95% CI)	p value	**Apps** OR (95% CI)	p value	**Video-conferencing** OR (95% CI)	p value
Confidence and competence	1.12 (1.08 - 1.16)	**< 0.001**	1.11 (1.07 - 1.15)	**< 0.001**	1.07 (1.03 - 1.1)	**< 0.001**	1.05 (1.02 - 1.09)	**0.002**
Improving clinical practice	1.15 (1.05 - 1.26)	**0.003**	1.33 (1.18 - 1.5)	**< 0.001**	1.17 (1.077 - 1.28)	**< 0.001**		
Ease of use					1.15 (1.07 - 1.31)	**0.027**	1.21 (1.08 - 1.35)	**0.001**
Subjective norms	1.15 (0.98 - 1.34)	0.085					1.21 (1.07 - 1.37)	**0.003**
Age (in years)	0.95 (0.89 - 1.01)	0.095						
Years worked in diabetes education					1.09 (1.01 - 1.18)	**0.034**		
Paediatric experience^ (no/yes)							2.05 (0.88 - 4.77)	0.096
Employment major city (no/yes)					2.87 (1.04 - 7.0)	**0.041**		
Constant: B (SE)	*-12.00 (3.25)*		*-19.25 (3.49)*		*-15.68 (2.63)*		*-8.97 (1.49)*	
Omnibus test of model coefficient: Chi²	*134.94*		*131.18*		*115.79*		*88.96*	

Backward: Logistic Regression. CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications. ^Working with respective patients with type 1 diabetes.

Predictive factors were shown to relate both positively and negatively to reported technology use (Figure 7b; Table 16). As for intention to use, diabetes educators' confidence and competence consistently positively predicted actual usage of all four technologies, as did preparation (intentions and training). Years worked in diabetes education positively predicted diabetes educators' reported use of both CGM and apps; experience working with paediatric patients with type 1 diabetes positively predicted CGM use. However, lack of ease of use was a negative predictor, or deterrent, of CSII and CGM usage. Subjective norms were again of importance, negatively predictive of use of apps, with perceived negative effects for clinical practice linked to lower use of video-conferencing.

Discussion

Our research indicates discrepancies and dissonance between diabetes educators' strongly positive intentions to use common diabetes-related technology for patients with type 1 diabetes and their reported actual usage, which is occasional and not likely to be adequate to support effective disease management or patients' communication and engagement with healthcare services. It also highlights key factors that can be targeted to address this gap.

Table 16: Independent predictors of diabetes educators' reported use of common diabetes-related technologies for patients with type 1 diabetes

Dependent	**CSII**		**CGM**		**Apps**		**Video-conferencing**	
Independent	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value	OR (95% CI)	p value
Confidence and competence	1.14 (1.07 - 1.2)	**< 0.001**	1.17 (1.1 - 1.25)	**< 0.001**	1.12 (1.07 - 1.18)	**< 0.001**	1.12 (1.07 - 1.17)	**< 0.001**
Improving clinical practice							0.92 (0.85 - 0.99)	**0.019**
Preparation (intentions and training)	1.23 (1.07 - 1.43)	**0.005**	1.16 (1.01 - 1.33)	**0.031**	1.26 (1.11 - 1.42)	**< 0.001**	1.15 (1.02 - 1.31)	**0.025**
Ease of use	0.75 (0.63 - 0.9)	**0.002**	0.72 (0.58 - 0.9)	**0.003**	0.89 (0.79 - 1.02)	0.086	0.87 (0.75 - 1.0)	0.053
Subjective norms	0.84 (0.67 - 1.04)	0.103			0.76 (0.65 - 0.89)	**< 0.001**		
Age (in years)	1.06 (1.0 - 1.13)	0.061						
Years worked in diabetes education			1.28 (1.1 - 1.49)	**0.001**	1.12 1.02 - 1.22)	**0.022**		

Presently ADEA credentialled (no/yes)		0.24 (0.05 - 1.23) 0.087		
Paediatric experience^ (no/yes)		5.10 (1.41 - 18.42) **0.013**		
Employment major city (no/yes)				2.25 (0.89 - 5.69) 0.085
Constant: B (SE)	*-3.59 (2.74)*		*-4.41 (1.59)*	*-2.94 (1.43)*
Omnibus test of model coefficient: Chi²	*71.96*	*133.46*	*99.77*	*95.13*

Backward: Logistic Regression. ADEA = Australian Diabetes Educators Association.
CSII = Continuous subcutaneous insulin infusions. CGM = Continuous glucose monitoring systems.
Apps = Smartphone and tablet applications. ^Working with respective patients with type 1 diabetes.

To increase technology adoption, diabetes educators' confidence and competence, their preparation (intentions and training) and their perceptions of the ease of use of the technologies are all important. Education has been widely reported as crucial to support change in these areas [312-316], and may be targeted to help address these predictive factors. With technology use in type 1 diabetes management increasing this should feature as part of routine continuing professional development for those who care for people with diabetes. The form in which this is delivered is likely to influence its uptake and effectiveness. The principles of adult learning [317] mesh with these findings to suggest such education should support diabetes educators as autonomous and self-directed learners, should be goal and relevancy focused and contain elements of experiential learning. There is potential for the Australian Diabetes Educators Association to expand their role by initiating, promoting and/or developing and making available relevant educational programs.

Other influences were subjective norms and technologies' perceived contribution to improving clinical practice; both could be addressed locally through, for example, experiential evidence-based workshops led by respected opinion leaders. Broadening diabetes educators' clinical experience by rotating local placements might also be helpful. Young adults' experiences of paediatric diabetes care have been reported as significant influences on their expectations of care as they transition to adult-based diabetes care, with unmet expectations linked to care disengagement [52, 57, 62]. Clinical placements across paediatric and adult diabetes care settings may be one means to increase diabetes educators' exposure to a range of care models as well as technologies, and better align the norms of practice in different settings for greater consistency of experience for young people and young adults.

Findings relating to video-conferencing were notably different to those of these other technologies. This was not surprising because this technology is used for rather different purposes; a means of conversing with patients rather than routine day to day clinical care. There are obvious differences in need for this technology, and hence exposure, for those in cities compared to regional, rural and remote areas. However, participants may also have interpreted these questions differently. Some may have responded based on experiences with video-conferencing in the form of personal communication software such as Skype™ and FaceTime®, whereas others may have been thinking of commercial systems managed by healthcare organisations; these differing systems, contexts, security concerns and technology performance may have influenced diabetes educators' reported attitudes and intentions. For the future, personal use of these and other diabetes-related technologies should be investigated, and how this may influence professional attitudes and behaviours, and other barriers and supports to technology use in a clinical setting.

Study limitations include the potential for responder bias and use of self-report data, intrinsic to survey design. Use of an online survey may have also pre-selected technology-oriented clinicians. Strengths derive from the history and rigor of the development of the model and the ensuing questionnaire instrument. Recruitment was successful across a wide and diverse geographical and sociological area, and may well have achieved a sample representative of eligible Australian Diabetes Educators Association membership.

Conclusions

This research is important because it explores previously little-examined attitudes and behaviours of an essential professional group supporting people with type 1 diabetes. Findings indicate discrepancies and dissonance between diabetes educators' strongly positive intentions towards use of common diabetes-related technology for patients with type 1 diabetes and their reported actual usage, which is only occasional and probably inadequate for patient support. Continuing education using the principles of adult learning may be key in supporting diabetes educators to align their intentions with their practice. Embedding engagement with technologies within diabetes educator practice, may help maintain and improve patients' communication and engagement with diabetes services, and with this their self-management of their diabetes. Whilst this may necessitate some resource reconfiguration, findings suggest how this may be approached in order to maximise realisation of the potential benefits of these new but now common diabetes-related technologies.

Summary

The survey of diabetes educators (n = 228) across Australia found discrepancies and dissonance between respondents' intentions and behaviours (intentions to use and reported technology use in patients with type 1 diabetes). One of the important discrepancies was that intentions to use the technologies were at a higher level than their actual use, which was relatively low. This was where dissonance occurred because such a low level of use was not likely to provide significant support to people with type 1 diabetes for disease management, communication and engagement with healthcare services.

To increase technology adoption, diabetes educators' confidence and competence, their preparation (intentions and training), their perceptions of the ease of use of the technologies, subjective norms and technologies' perceived contribution to improving clinical practice are all important. Continuing education and experiential learning may be key in supporting diabetes educators to align their intentions with their practice and service changes to facilitate this.

Collectively, findings expand upon those of chapter 5, which had highlighted the general lack of skilled healthcare professional support available for CSII use. With findings from this paper indicating elements that can be targeted to effect change, across Australia there is an opportunity for service and practice development. Adoption of policies that require diabetes educators to include technologies within their everyday practice may enable delivery of higher levels of support to young adults with type 1 diabetes.

CHAPTER 7. DIABETES EDUCATORS' EXPERIENCES, PECEIVED SUPPORTS AND BARRIERS TO USE OF COMMON DIABETES-RELATED TECHNOLOGIES

Study rationale

The telephone interviews of healthcare professionals who deliver service support for CSII users flagged a number and range of barriers to delivery of this very specialist form of service support (chapter 5). Picking up a broader theme of technology use and considering support for people with type 1 diabetes more generally, the survey of diabetes educators (chapter 6) found that their current use of common diabetes-related technologies was at a relatively low level, and not likely to provide sufficient support for disease management or their communication and engagement with healthcare services. However, little information is available on diabetes educators' perceived experiences, supports and barriers to use of common diabetes-related technologies (CSII, CGM, apps and video-conferencing) for people with type 1 diabetes, data that could be used to inform comprehensive service and education planning. This chapter addresses this limitation, providing information to support future policy and strategy development. It incorporates the first published in-depth study which identified the perceived experiences, supports and barriers to use of common diabetes-related technologies (CSII, CGM, apps and video-conferencing) by diabetes educators across Australia, for people with type 1 diabetes.

James. S, Perry. L, Gallagher. R and Lowe. J (2016).

Diabetes Educators: Perceived Experiences, Supports and Barriers to Use of Common Diabetes-Related Technologies.

Journal of Diabetes Science and Technology, 1-:5, 1015 - 1021.

The paper is appended at Appendix 15.

Journal choice rationale

The rationale for choice of Journal of Diabetes Science and Technology was set out in chapter 6.

Paper 6

Aims

This study aimed to examine diabetes educators' perceived experiences, supports and barriers to use of common diabetes-related technologies for people with type 1 diabetes.

Methods

Design and data collection

This was a qualitative study undertaken June - August 2014 using an ethnographic design. Data were collected by individual semi-structured telephone interviews, allowing topics to be explored in depth, with confidentiality, providing opportunities to probe and encourage detailed responses, and enabling participation across wide geographical distances [318].

The interview schedule was developed by research team members, and piloted with two Canadian based diabetes educators (Appendix 16). Topics included participants' experience of working with each type of technology, the impact of supporting these technologies on workload, perceived supports and barriers to their use, and the influence of work environments on uptake and capacity. Participants were asked to briefly describe their professional background and geographical location.

Sample

A purposive sample was collected from members of the Australian Diabetes Educators Association; the leading Australian organisation for multidisciplinary healthcare professionals who provide diabetes education and care. This sampling technique was

chosen to obtain a wide cross-section of participants with collective experience with the four technologies. Participants were eligible for the study if they had current Australian Diabetes Educators Association membership, current or past experience as a diabetes educator in Australia and in use of CSII, CGM, apps and/or video-conferencing. They were required to be able to converse in the English language, have access to a telephone and an email address. Recruitment ceased when data saturation had been reached and it was deemed there were no new data to gather.

Procedure

Two hundred and thirteen members who responded to advertisements in the Australian Diabetes Educators Association newsletter and completed the anonymous web-based survey (chapter 6), were supplied with study information and invited to participate (Appendix 17); interested participants provided their contact details. Interviews were conducted by the first author, whose professional standing as a diabetes educator facilitated development of the trust necessary to share private, sensitive or controversial details [319, 320]. It also enabled understanding of participants' frame of reference, and potential exploration of contextual points or ideas raised. Personal pre-conceptions and biases were addressed through maintenance of a reflexive journal, peer debriefing and triangulation [321]. Field notes were collected during and after each interview, which was audio recorded after an introduction where confidentiality principles were reinforced.

Ethical approval for the study was obtained from the University of Technology Sydney Human Research Ethics Committee (UTS HREC 2014000287, 4th June 2014 (Appendix 13), and UTS HREC 20140005, 4th September 2014 (a variation)).

Data analyses

Audio data and field notes were transcribed verbatim into Microsoft Office Word 2010™, de-identified and imported into NVivo™ 10 software. Data were analysed using Gibb's [294] framework, which entailed transcription and familiarisation, code building, theme development, and data consolidation and interpretation. Transcripts were available to participants for comment. They were read by all authors; the first author initiated coding and theme organisation which was developed and discussed with all authors to reach consensus.

Results

Interviews were conducted with diabetes educators (n = 31) who worked across metropolitan, regional and rural areas (Table 17). Most were female (90.3%) and Registered Nurses (96.8%), although working at differing levels of expertise and responsibility. Interviews lasted mean (SD) 35 (8.75) minutes.

Table 17: Interviewee characteristics

	n	**Male**	**RN**	**APD**	**Age** (mean (SD))*
Rural	6	2	6	0	48 (10.6)
Regional	9	0	9	0	53 (4.7)
Metro	16	1	15	1	49.6 (5)
Total	31	3	30	1	50 (6.4)

n = Number. RN = Registered Nurse. APD = Accredited Practising Dietician.
* = in years. Metro = Metropolitan

Participants overwhelmingly perceived technology use as personally burdensome, when considering the increased demands that this placed on themselves and the need to occasionally use personal resources. Many wanted help, particularly to support patients with CSII. Three themes detailed perceived supports and barriers to involvement with common diabetes-related technologies in the care of patients with type 1 diabetes: access to technology, availability of support and technological advances.

Access to technology

Access to technology was often difficult, both for patients and diabetes educators. Patient access to CSII was limited by device costs, seen as prohibitive for many. The current Australian Government subsidy, whilst considered beneficial, was not available to young adults, many of whom were unable to self-fund these devices. The absence of government CSII device support after age 18 years resulted in some patients being unable to replace and so continuing to use old and defective equipment. Participants felt obliged to support patients with minimally functioning devices, even though it was not seen as in their best interests:

> "*I had a chap the other week that didn't even have a face on his pump* [CSII] .... *he's still using it six months after I asked him not to.*" (diabetes educator 23: metropolitan)

Another barrier to access was the lack of systematic processes for determining the balance of benefit and risk from device use for individual patients. Often diabetes educators were expected to take responsibility to gate keep this technology without formal organisational policy or professional guidance. As one diabetes educator stated:

"It's generally up to the diabetes educator who will see the patient first. They will deem if they think it [CSII] *is suitable."* (diabetes educator 53: metropolitan)

Similar access difficulties were described in relation to CGM technology. Participants, especially those working in hospitals, expressed frustration with their lack or limited access to CGM devices, transmitters and sensors, and that they often did not have adequate software and computer access to download CGM or CSII data direct from devices. They also perceived the cost of CGM technology as prohibitive to consumers, and appreciated when diabetes centres could fund CGM sensors. This occurred where diabetes educators judged there was clinical need, a decision seldom underpinned by any formal policy or guidance. Where hospitals, and sometimes private diabetes educator practitioners, loaned CGM devices and/or transmitters to patients, this was seldom covered by a specific organisational infection control policy; devices were however routinely cleansed upon return. Highlighting co-operation between paediatric and adult diabetes healthcare services to increase CGM access in a regional setting, one diabetes educator stated:

"The paediatric unit actually paid for the device [CGM] *.... I get the adults to pay for their sensors."* (diabetes educator 92)

Difficulties with access were also described in relation to apps. Participants expressed their frustration that apps were not available across all brands and models of smartphones and tablets. They highlighted that many patients lack access to this technology and Wi-Fi coverage. However, this was also not provided to many diabetes

educators by their employers, and consequently they resorted to using their personal smartphones and Wi-Fi accounts.

Access to video-conferencing was mixed. Participants employed within hospitals, particularly in metropolitan areas, largely reported access to commercial video-conferencing systems, usually shared across health disciplines. However, the cost of such systems was prohibitive for smaller diabetes services, general practices and private diabetes educator practitioners. Instead, many participants in regional and rural localities used free personal communication software such as Skype™. Originally banned, Skype™ use was now often approved. However, network coverage in non-metropolitan areas was often erratic, especially outside of school hours, resulting in inconsistent visual and sound quality, and outages. This often deterred use.

Availability of support

Time constraints were a barrier to participants' involvement with all technologies; CSII and CGM, particularly, were perceived to negatively impact workload. Recognising the number of interactions required to commence a patient on CSII, one diabetes educator stated:

> "*We've got* [small number] *educators so if a person wants to go on a pump* [CSII] *you've got one educator out* (i.e. solely preoccupied with that patient) *for a day and a half."* (diabetes educator 22: metropolitan)

Participants expressed their frustrations at insufficient diabetes educator staffing for their patient numbers and lack of staff skilled in CSII and CGM, in particular.

Considering the increasing uptake, they were anxious how they would cope into the future, especially within paediatric settings. However, they valued the support received from diabetes educator colleagues.

Participants also expressed their discomfort working with patients who had commenced CSII elsewhere, for the demands this placed on themselves and their already strained diabetes service. Many in regional and rural localities were suspicious that funding incentives from CSII companies, rather than patient needs, drove decisions to commence patients on this method of insulin delivery in metropolitan centres. Their concern was that these patients later sought follow-up, and in the event of related ill-health, presented to their local diabetes service or hospital, which was often under-staffed and under-skilled for this.

> "*Multiple metropolitan centres …. would be happy to take a referral to initiate a pump* [CSII]*, but that's the end of the service provided.*" (diabetes educator 11: rural)

Limitations to Australian Government Medicare rebates meant that many private diabetes educator practitioners were unpaid for much of the work they undertook. This acted as a barrier towards further involvement with CSII, CGM and video-conferencing. One diabetes educator stated:

> "*The patients have to pay to see me or they had EPCs* [enhanced primary care plans - government funding] *that they could put through. I put in a lot of time and effort that I was never reimbursed for.*" (diabetes educator 9: regional)

Managers and physicians could be supportive towards technology use, for example, by advocating for and securing related funding. However, they could also act as barriers to involvement. Medical staff who had qualified from medical school years earlier were viewed particularly negatively when considering their views towards use of apps and CSII. Especially in community and general practice settings, little hands-on support was available to diabetes educators for CSII and CGM use. General practitioners were perceived to have limited involvement in the care of patients using these technologies, referring any issues to diabetes educators. Participants also highlighted endocrinologists' under-use and occasional unwillingness to use video-conferencing.

There was concern at lack of funding for on-call diabetes educator staffed services to provide advice in emergencies for CSII and CGM users outside of office hours: device failure, acute diabetes-related complications and sick-day management, for example. In rare instances where on-call services were available, these were staffed by physicians with limited knowledge of these technologies. As a consequence, many participants provided selected patients with their personal contact details; criteria for such decisions were unclear:

> "*There's no point in them going to hospital because …. They are not upskilled with using the pump* [CSII] …. *If we can avoid an admission, I prefer to give them my personal mobile number.*" (diabetes educator 12: regional)

Support was available from the manufacturers of CSII and CGM technologies through telephone help-lines for patients and healthcare professionals. These were deemed very

helpful by diabetes educators, though concerns were raised at calls being diverted to agents in other countries and the sometimes "textbook" advice provided. Companies also loaned devices and transmitters, and provided consumables, trial sensors and ongoing education. However, for video-conferencing, participants identified very limited and sometimes complete absence of organisational training. They also had concerns about the support and facilities at connecting sites. Information technology departments were seen as both supportive and barriers to involvement with this technology.

Technological advances

Participants had difficulty keeping up to date with advances in design and programming of CSII and CGM devices. They relied almost exclusively on information from companies. They struggled to maintain the regular software updates required for full functioning, in the face of barriers to downloading, organisational hurdles and computer firewalls.

Similar difficulties were reported in keeping up to date with apps, especially because of their increasing numbers and the workload burden this represented. Participants primarily relied on obtaining information at conferences, but also from diabetes educator colleagues, companies, patients and professional magazines:

> "*Everybody's so busy rowing the boat that they don't have time. Our flow through is not dropping, it's getting bigger …. and you get less funding, less resources*." (diabetes educator 27: metropolitan)

Diabetes educators were unable to make best use of data collected through apps and CGM systems. They highlighted concerns regarding the formats in which data were provided, based on programming deficiencies and the difficulties experienced interpreting such data. Patients were also not always good at providing complete information, with records omitting important details such as carbohydrate consumption and exercise undertaken.

> "*They send me information and you just can't work out what time it was and all sorts of things …. it's not set out in a manner that is friendly for us.*" (diabetes educator 23: metropolitan)

Discussion

Findings provide important insights into diabetes educators' experiences and perceptions of what supports and limits the use of common diabetes-related technologies for patients with type 1 diabetes in Australia. Overall, themes demonstrated that whilst care was usually well-intentioned it was more often fragmented and inconsistent, and not often enough delivered with appropriate technology expertise. Change is clearly needed at multiple levels of the Australian healthcare system to facilitate diabetes educators' technology adoption and realisation of the potential of these technologies for improved patient outcomes and support.

Firstly, findings reveal that diabetes educators need support to attain and retain the skills required to deliver these essential components of care. They mesh with findings from the anonymous web-based survey (chapter 6), which highlighted the need for diabetes

educators' ongoing education to promote technology adoption. Though the support need around skills may lessen in the future with the generational ages of participants predominantly not indicative of 'digital natives' [322], in the meantime organisational and managerial support in the form of funding and time allowance (both study time to gain the skills and time to use them) would assist, as would rotating placements across and between paediatric and adult diabetes care settings. Besides increasing diabetes educators' technology exposure, this may better align the norms of practice in different settings for greater consistency of patient experience (chapter 6). Mentorship schemes should also be established and promoted; external stakeholders such as the Australian Diabetes Educators Association may be able to assist [323]. They could also assist by providing periodic detailed summaries of evolving CSII and CGM systems and apps, in view of participants' difficulties keeping up to date. However, whilst education is a necessary pre-requisite, it is not a panacea.

Support for diabetes educators in providing technology-based care delivery could involve service reconfiguration. In some areas, this may necessitate reallocation of staffing and resources and improved infrastructure. Cross-coverage from areas where technology-based expertise exists would also assist, enabled by maximisation of video-conferencing use. Besides facilitating diabetes educator peer support and professional development, video-conferencing could also be the medium to provide support directly for patients, to make communication more flexible and care more efficient [175]. Information technology departments have an important role in this, and access to such support should be maximised.

A review of policy and strategy is also required of the allocation of devices to patients, of the role of patients in choosing insulin delivery and blood glucose monitoring technologies, and the processes for ensuring support from healthcare providers. The absence of consistent policies relating to CSII and CGM compounded the confusion reported both within and between services. Recent Australian CSII clinical guidelines feature assessment of patient suitability for CSII use [97, 98], and state guidelines make recommendations for in-hospital CSII care [299]. These should be promoted and adopted, and local policies formulated from these documents to translate guidelines into practice.

Australian Government policy for access to common diabetes-related technologies, especially CSII, requires review. The current government CSII device subsidy ceases once a child reaches age 18 years [293]. However, considering the importance of optimal glycaemic control to minimise diabetes complications, and hence their associated costs (chapters 2 and 3) [29, 296], there is a case to extend the subsidy to enable CSII use to continue safely through the often impoverished early adult years when glycaemic control often deteriorates.

Review is also required of the Australian Government Medicare rebates available to private diabetes educator practitioners; lack of reimbursement was reported as a barrier to diabetes educators' involvement with CSII, CGM and video-conferencing. Existing rebates do not take full account of the time required to commence a patient on CSII, reported as median 18.6 hours and 14.1 interactions over 11.8 weeks [98]. Rebates only cover five 'face-to-face' visits and do not fund consultations undertaken via video-

conferencing, although healthcare professionals other than diabetes educators are able to utilise this technology [324].

Study limitations include that recruitment methods targeted only members of the Australian Diabetes Educators Association, and participants self-selected; findings may not be representative of all diabetes educators [325]. There was no quantification of participants' experience with the technologies; limited exposure may have influenced perceptions. Nonetheless, strengths derive from the number of interviews undertaken, recruitment across diverse and wide sociological and geographical areas, and the depth and detail of data obtained on this little explored topic.

Conclusions

This research provides important insights into the perceptions of an essential professional group in the care of patients with type 1 diabetes, in relation to what supports and deters use of common diabetes-related technologies. Difficult access to technology, limited availability of support, and relentless but inaccessible technological advances influenced diabetes educators' involvement. Findings suggest that to maximise technology adoption and support many diabetes educators need to attain and retain the skills required to deliver this essential component of care. Further, there is a need for review of policy and strategies, followed by reconfiguration of services to support care delivery and realise the potential benefits of these new but now common diabetes technologies.

Summary

Findings from these interviews with diabetes educators (n = 31) across Australia found that the use of technology in the care of patients with type 1 diabetes was overwhelmingly perceived to be burdensome and thus likely to inhibit their engagement. Findings demonstrated that whilst care was usually well-intentioned it was often fragmented and inconsistent, most often provided by a small number of diabetes educators with technology expertise. Findings reinforce the gaps between young people's expectations (chapter 4) and healthcare professionals' expectations (chapter 5), and the capacities and realities of service delivery.

Three themes involving common diabetes-related technologies emerged from the data: access to technology, available support and technological advances. Difficulties around patient access to technology occurred partly as a result of technology costs and limitations to Australian Government policy. For diabetes educators, departmental support, a lack of systematic processes and available infrastructure influenced access. Time constraints and insufficient diabetes educator staffing, and limitations to Australian Government Medicare rebates influenced the support that diabetes educators were able to provide. Finally, technological advances meant that many diabetes educators had difficulty keeping up to date.

Collectively, findings highlight that to realise the potential benefits of relatively new but common diabetes technologies across Australia, many diabetes educators need to attain and retain the skills required to deliver this essential component of care, and their managers need to be able to support them in this. Findings suggest how this may be

approached. Further, policy and strategy review is required, with reconfiguration of services to better support care delivery.

CHAPTER 8. DISCUSSION

The aim of this thesis was to examine the current state and future opportunities for Australian healthcare services to support young adults with type 1 diabetes. Descriptive accounts have flagged the psycho-social challenges to type 1 diabetes self-management and the difficulties encountered by young adults in obtaining age-relevant specialist service support. However, no review had been undertaken to demonstrate the prevalence of the vascular complications (retinopathy, nephropathy and/or hypertension) that are the consequence of sub-optimal diabetes self-management. There had also been no examination of factors potentially predictive of their development in this important age group. An examination of the international literature (chapter 2) revealed a paucity of data generally, and (at the time of the initial systematic review) no Australian data, an important limiter to determination and prioritisation of diabetes healthcare service needs. Subsequent analysis of routinely collected data (chapter 3) indicated that considerable numbers of young adults with type 1 diabetes in Australia have vascular complications, consistent with systematic review findings.

The likelihood of any vascular disease (retinopathy, nephropathy and/or hypertension) increased with higher blood glucose and, when considering nephropathy specifically, with hypertension (chapters 2 and 3). Inadequate glycaemic control is also widely recognised as disruptive of employment, social and family life, and to generate high financial cost [29, 258-261, 263]. The support of diabetes healthcare services may be crucial because blood glucose and blood pressure are both amenable to early control. Regular contact with diabetes healthcare services for type 1 diabetes management and complications screening using best practice guidelines, affords the greatest chance to

support type 1 diabetes self-management, and early complication detection, treatment initiation, regular monitoring and secondary prevention.

However, regular contact with diabetes healthcare services was demonstrated as unreliable. Analyses of case note data (chapter 3) and the survey of young people with type 1 diabetes and their parents (chapter 4) demonstrated low attendance rates for routine preventative healthcare services, consistent with other Australian and international data [41, 57, 141, 250, 254, 326, 327]. A recent survey of young people living with type 1 or type 2 diabetes in Australia found less than half of those aged 18 - 24-years (42%) were attending a diabetes service [326]. Respondents who had not seen a diabetes healthcare professional for 6 months or more were significantly more likely to consider their relationship with healthcare professionals as problematic.

At the same time, rates of unplanned healthcare contacts for diabetes-related matters were high (chapters 3 and 4). Unplanned contacts, mostly through Emergency Department presentations, can be an indicator of poor access, poor quality or age-inappropriate preventive diabetes healthcare [31]. Acute healthcare services are often not well-placed as settings to learn diabetes self-management, with the Emergency Department presenting a particularly busy and chaotic environment, challenged by overcrowding, unpredictable census and limited staffing [328-330]. Many hospital staff lack expertise in diabetes management, with studies having repeatedly demonstrated inadequacies in the diabetes knowledge of non-specialist nurses [331].

The identified high use of acute healthcare services by young adults with type 1 diabetes also represents poor cost-effectiveness for healthcare systems. DiabCo$t Australia Type

1, a retrospective, cross-sectional, self-reported survey of people with type 1 diabetes aged five years and older in Australia, reported hospitalisation as the largest contributor (47%) to direct healthcare costs of type 1 diabetes [29]. Though the provision of specialist care (7.7%), allied health (4.8%) and primary care (3.7%) contributed to cost, in the long run successful preventive care is less expensive than hospitalisation. High but avoidable use of acute healthcare services and inadequate diabetes self-management by young adults with type 1 diabetes is therefore not in the best interests of the consumer, the provider or the (tax-paying community) funder.

As a method of insulin delivery, CSII therapy offers potential to achieve tight glycaemic control, which can avoid or delay the onset of disease complications and thus the major sources of morbidity and mortality. The reality of the effectiveness of this technology for glycaemic control in type 1 diabetes, however, remains a matter of debate for both children and adults [10, 104-130], although a modest statistically significant difference of -0.2 (95% CI -0.28 to -0.12, $p < 0.0001$) favouring CSII has been reported by the Australian Type 1 Diabetes Guidelines Expert Advisory Group [10]. When considering adults only, the mean difference in HbA1c was reported as -0.16% (95% CI -0.33 to -0.01, $p = 0.06$), again in favour of CSII. Other benefits of CSII use compared to multiple daily injections have been more clearly demonstrated. These include less fear of hypoglycaemia, improved quality of life due to increased meal-time and carbohydrate flexibility, and greater convenience and discretion of insulin delivery. Decreased mortality and favourable health economic outcomes have also been reported [10, 103-140, 276-279].

Despite the relatively high use of CSII amongst children and adolescents with type 1 diabetes in Australia, with the peaks of Australian CSII usage occurring in the 10 - 14 years age group and 40% of all new users between 2008 - 2010 being under 18 years of age [141], there was limited information about the attitudes, perceptions and everyday experiences of diabetes management amongst young Australians using this technology. Further, little was known of the intentions of the paediatric population in relation to CSII use once they become adults [103, 104]. Collectively such factors limit determination and prioritisation of needs in the planning of future Australian adult-based diabetes healthcare services, omissions that were addressed in chapter 4.

The survey of young people with type 1 diabetes and their parents (chapter 4) revealed generally positive attitudes and perceptions of self-efficacy and diabetes management. Nonetheless, young people were moderately disturbed by their diabetes and reported experiencing sub-optimal management outcomes. Though CSII users were generally satisfied with this technology, it did not appear to be used to its full potential. Findings also indicated young people's care expectations around CSII therapy; information of use for comprehensive adult-based healthcare service and education planning.

Findings from interviews and the survey of diabetes educators, however, identified the complexity of providing support for patients using common diabetes-related technologies, particularly CSII therapy (chapters 5 - 7). Gaps between young people's (chapter 4) and healthcare professionals' expectations, and the capacities and realities of service delivery were highlighted. The relatively low level of technology use that was revealed was unlikely to provide significant support to people with type 1 diabetes for disease management, communication and engagement with healthcare services. Factors

common across studies included difficulties with access, service co-ordination and insufficient range of healthcare professional expertise, all three of which are amenable to change. Difficulties were encountered by some patients with type 1 diabetes around access to expert diabetes healthcare, when considering use of insulin delivery and blood glucose monitoring technologies. Many healthcare professionals also experienced limited support, while some patients with type 1 diabetes and healthcare professionals experienced difficulty with access to varying common diabetes-related technologies. Service co-ordination, however, was undermined by lack of common data systems, communication infrastructure and connectivity, and an absence of consensus or definition for some key organisational processes, mostly when considering CSII. Fragmented and inconsistent care also reflected lack of specific expertise in some locations, considered essential to support CSII use particularly.

Thesis findings flag challenges for the future. The next wave of disease self-management technology is already on the horizon: the United States Food and Drug Administration have recently approved the first hybrid closed-loop insulin delivery and blood glucose monitoring system, that automatically increases, decreases and suspends insulin delivery in response to CGM measurements [151]. A study on the safety and effectiveness of in-home use of a hybrid closed-loop system has already demonstrated a significant decrease in HbA1c for adolescent (mean (SD age 16.5 (2.3) years) and adult (44.6 (12.8) years) patients with type 1 diabetes (from 7.7% (0.8%) to 7.1% (0.6%), $p < 0.001$; and from 7.3% (0.9%) to 6.8% (0.6%), $p < 0.001$, respectively) [332]. Ultimately, if diabetes healthcare services cannot provide adequate support to make full use of current technologies, they will likely have difficulty making use of the potential of next generation technologies, and in meeting the needs and preferences of the next

generation of young adults with type 1 diabetes. Patients are becoming increasingly informed about therapeutic options available with the advance of the internet and social media; with increased technology marketing and availability, they may drive demand [333-336]. Many healthcare professionals may soon have little option but to provide care that involves use of insulin delivery and blood glucose monitoring technologies. The survey of young people with type 1 diabetes and their parents indicated that a sizeable proportion of these young people will want to take advantage of CSII technology when accessing adult-based diabetes healthcare services (chapter 4). The Australian Government's recently announced CGM funding for people with type 1 diabetes aged 21 years or less [337] will also increase demands on healthcare professionals and diabetes healthcare services to provide appropriate technological support.

There are, however, possible solutions to improve the health outcomes of young adults with type 1 diabetes in Australia, and the support of healthcare professionals providing related care. These solutions centre around the role of primary care, promotion of adult-based diabetes healthcare engagement, changes to adult-based diabetes healthcare service configuration and delivery in ways that meet the needs of young adults with type 1 diabetes and that are acceptable to them, and increased capacity and opportunity for use of common diabetes-related technologies, particularly CSII. There is also a need for consideration of healthcare services dedicated to the care of adolescents and young adults with type 1 diabetes around the time of transition to adult-based programs.

Service solutions

1. Transition preparation

The potential for dedicated type 1 diabetes healthcare services for adolescents and young adults should be explored. Medical systems, not just for type 1 diabetes, are arranged separately and differently around children to those for adults, with transition between them not clearly the responsibility of either. This arrangement serves young adults poorly because of key differences between the paediatric and adult systems in their approach and provision of type 1 diabetes care, in the type and amount of support, decision-making, family involvement and consent [10, 47]. Regardless of models of care utilised, this does not eliminate transition issues which, if not undertaken in an appropriate and timely way, can increase the risk of disengagement from adult diabetes healthcare services [7, 41, 55, 62, 73-75].

Comprehensive transition is essential as it affords the greatest chance of ensuring knowledge and skills adequacy to enable informed health decision making around disease self-management behaviours, problem solving and active collaboration with the healthcare team. The importance of children and young people having equitable access to healthcare services and improved systems to optimise health outcomes, has recently been indicated in the Australian National Strategic Framework for Child and Youth Health [51]. Australian recommendations for the care of young adults with type 1 diabetes, which includes the transition period from paediatric to adult care systems, are available [10, 50]. Care for adolescents generally and during this transition period has also been the focus of international attention through, for example, the Lancet Commission on adolescent health and well-being [338], a position statement on diabetes released by the American Diabetes Association [7] and a United Nations General

Comment [339]. The components of effective structured transition between medical systems specific to Australia should also be explored, and policy established, on the basis that this will help improve the readiness for transition.

The transition of adolescents and young adults from paediatric to adult-based diabetes healthcare systems should occur in a purposeful, structured and collaborative manner [1, 7, 10, 36, 42, 50]. However, few diabetes services conduct transition in a systematic and rigorous fashion [1, 35, 37, 57-65]. The challenges in bridging two separate health models of care and two distinct busy healthcare services have also been reported for numerous other diseases [340], and has been the subject of a paediatric chronic diseases transition framework by the Government of Western Australia [341]. Only 12% of 14 - 17-year old's living with type 1 or 2 diabetes in Australia, and 26% of those in the 18 - 24-year age group have been reported to know which adult diabetes healthcare service they were going to transfer to. Further, almost half (49%) of young adults (aged 18 - 24 years) are reported to have never discussed transitioning from a paediatric to an adult-based diabetes service with a healthcare professional [326], and for 27% of those that had, it was a general practitioner who had helped them prepare to make the change. These findings illustrate a potentially pivotal role for primary care in the well-being of young people with type 1 diabetes as they transition to adult-based diabetes healthcare services [7, 10, 79, 286, 326].

2. Primary care

Primary care already has an important role in maintaining young adults with type 1 diabetes in contact with health services, providing preventive healthcare and input around day-to-day health issues. It is generally assumed that primary care takes up a

greater role and responsibility for healthcare provision when there is no accessible adult diabetes service [10]. However, there is a paucity of data as to whether this happens. In Australia, it is expected that those who are eligible for Medicare coverage, regardless of health status, register with a single primary care service, with services accessed elsewhere only by exception. Data are lacking on how this plays out in practice but it has been reported that around 14% of patients with diabetes 'doctor shop' in other countries [342]. Reasons for accessing multiple primary care providers include variations in consultancy fees and appointment waiting times. Seeking assistance from multiple healthcare professionals is a major obstacle to the provision of efficient and comprehensive type 1 diabetes healthcare, and in promotion of stable and enduring relationships between the primary care provider and the person with type 1 diabetes, especially as they begin to transition to adult-based diabetes healthcare services. Specific recommendations to promote contact of people with type 1 diabetes with primary care, and to improve management outcomes are beyond the scope of this thesis. Solutions to promote contact with a single practice and develop the expertise of primary care in this area should be explored.

Consideration should be given to the use of financial incentives to promote the engagement of young adults with type 1 diabetes with primary care in Australia, their engagement with healthcare professionals practising in other levels of care, and related management outcomes. The use of Australian Government financial incentives through the Medicare Benefits Schedule, including those relating to Chronic Disease Management items (formerly known as Enhanced Primary Care), are reported to have resulted in improvements in process and clinical outcomes [343]. Thesis findings indicate that limitations to Australian Government Medicare rebates also mean that

many private diabetes educator practitioners are unpaid for at least some of the work they undertake. This acts as a barrier towards further involvement with CSII, CGM and video-conferencing (chapter 7). Expansion of the Australian Government's Medicare Benefits Schedule may therefore be warranted.

Review of financial incentives to promote engagement of young adults with type 1 diabetes with primary care in Australia, and related management outcomes should include exploration of pay-for-performance incentives. In Australia, the completion of healthcare plans and annual cycles of care have been reported to have a lack of influence on HbA1c, cholesterol, quality of life, depression or diabetes-related stress, and only a small positive influence on blood pressure [344]. The efficacy of pay-for-performance programs targeting both type 1 and type 2 diabetes that have been implemented elsewhere is also questionable.

The use of diabetes incentive codes appear to have led to minimal improvement in the quality of diabetes healthcare in Ontario, Canada, at both the population and patient level, with physicians participating in these enhanced billing incentive programs already providing guideline-recommended care prior to introduction of these incentives [345, 346]. Similarly, in the United Kingdom, the adoption of the Quality and Outcomes Framework to facilitate the management of people with type 1 diabetes and other chronic conditions in general practice (from 2004 onwards) appears to have had limited overall success. This framework placed a focus on paying general practice for the identification and management of people with a long-term condition, through achievement of evidence-based performance targets. Despite the quality of diabetes healthcare, which had already been increasing pre-adoption, having increased

significantly following the introduction, the accelerated rate of improvement was not sustained after 2005 when it reduced to that prior to adoption [347]. Between 2008 - 2009, it was estimated that only 32% of those with type 1 diabetes received all National Institute for Health and Care Excellence recommended care processes [348]. There were also inequalities in the recording of diabetes at general practices, with those in more deprived areas being less likely to have HbA1c, BMI and smoking status documented [349], and a lower-than-optimal level of healthcare planning with diabetes patients. For example, the proportion of people with diabetes who reported having discussed their healthcare plans and agreed self-care goals ranged from 23 - 58% [350] whilst a survey of primary care trusts showed that only 67% required a healthcare plan to be made [351]. Collectively, pay for performance incentives do not appear to promote patient engagement with diabetes healthcare services.

3. Promotion of regular diabetes healthcare service contact

Under current policy arrangements there are opportunities to promote regular contact with diabetes healthcare services by young adults with type 1 diabetes, which should be explored. Firstly, consideration should be given to a reduction in the quantity of disposable insulin pens and pen-fill cartridges that can be prescribed by physicians and Nurse Practitioners, especially in acute healthcare services. Currently, a single prescription for insulin may provide patients with quantities of insulin that mean they do not need to seek further physician or Nurse Practitioner contact for a lengthy time period. Secondly, insulin could also possibly be made available for purchase at pharmacies, not subsidised by the Australian Government as part of the Pharmaceutical Benefits Scheme [352], without the need for a prescription. Wider access to insulin may reduce the use of acute healthcare services for prescription-related matters. In Ontario,

Canada, insulin has been available to patients with type 1 diabetes for purchase at pharmacies without a prescription, for many years.

The Australian Government could also introduce conditions around access to subsidised blood glucose testing strips, and both CSII and CGM consumables via the National Diabetes Services Scheme, to promote healthcare professional contact [150]. Outside of registration requirements which necessitate healthcare professional input, there are presently no in-built facilitators or inducements to promote regular engagement with diabetes healthcare teams. Data on registration and usage are retained, but there is no linkage to clinical data in terms of glycaemic control or to hospital administrative data such as Emergency Department use and admissions. Data linkage, another technology, could potentially be used to support funding decisions and systematise healthcare service planning into the future.

Lack of common data systems, communication infrastructure and connectivity between diabetes healthcare systems also hamper follow-up and increase risk of healthcare disengagement, care duplication and missed opportunities to create large common data sets (chapters 5 and 7). The risk of patients being lost to follow-up was highlighted, flagging, at minimum, the need for integration of healthcare records on a mandatory rather than voluntary basis (chapter 5). The lack of common data systems may be improved through promotion and routine use of the Australian Government's 'My Health Record', a secure online electronic summary on an individual's key health information designed to be integrated into existing local systems [353]. The 'My Health Record' may be desirable for young adults with type 1 diabetes as they can view their own record on a smartphone or tablet device of their choosing. However, many are less

supportive of this particular form of national health e-record, with concerns having been raised around the laws and legislation governing and protecting, and patient control over, the 'My Health Record' which can be changed at any time [354]. Further, fears have been raised at personal and health data being sold to private corporations, such as when considering the sale of both the National Bowel Cancer and National Cervical Screening Registers by the Australian Department of Health to Telstra. The feasibility of using an electronic medical record for research has been discussed, and the broader impact electronic medical record systems may have beyond use in clinical care has been considered [355].

Together with the promotion of regular diabetes healthcare service contact, the factors and systemic barriers that make it challenging for physicians and patients to manage type 1 diabetes in partnership also need to be addressed [345].

4. Adult service redesign

Young adults with type 1 diabetes across Australia appeared to have equal but not equitable access to diabetes healthcare services, particularly in support of CSII therapy (chapters 5 - 7), which is consistent with other Australian and international data [254, 356-359]. A similar picture is seen to that of healthcare services for young adults with cancer, which also demonstrates actual and potential inequity [360]. When considering CSII, young adults with type 1 diabetes in rural and remote geographical areas are potentially doubly disadvantaged, considering the distances they have to travel for specialist healthcare, in addition to other limiting factors such as transport availability or operational hours of preventative care services [178].

Findings relating to the inequitable access to diabetes healthcare services around use of CSII are of particular concern, considering the preferences for CSII expressed by young people with type 1 diabetes and their parents (chapter 4) and recent data on CSII use in Australia. With 40% of all CSII users in Australia under 18 years of age, and approximately 19% of males and 14% of females with type 1 diabetes (ages 20 - 24 years) utilising this technology [141], it seems likely that use of CSII in young adulthood will increase in the future. Regardless of the method of insulin delivery, it may be that if young adults with type 1 diabetes are unable to get direction from their diabetes care team, they will either have to manage by themselves or seek advice from non-regulated sources, such as from family, friends, neighbours and social media. Either option presents risks and suggests that reconfiguration of some diabetes healthcare services and/or alteration in service delivery is warranted.

Consideration should be given to the development of new models of care to better support regional, rural and remote young adults with type 1 diabetes, promoting healthcare equity. Further, the development of new funding models that cost-shift to promote expansion of preventive care may recoup some of the expense of use of acute healthcare services for diabetes crisis management [346]. Many staff (predominantly in metropolitan areas) also expressed the need for improved and perhaps dedicated services for CSII users (chapter 7). Dedicated services for CSII support could promote development of a structured team approach, potentially enabling more consistent patient follow-up and perhaps better patient outcomes from CSII usage. However, this is not a full solution considering healthcare professionals had also highlighted that in the event of ill health, CSII users present to their local healthcare service which is often inadequately resourced to assist (chapters 5 and 7). Recommendations around age

relevant models of care for young adults with type 1 diabetes are beyond the scope of this thesis, however the components of this should be explored. Consideration should be given to the use of professionally led support groups which have been shown to improve glycaemic control and self-motivation, decrease self-reported diabetes burden and facilitate peer-to-peer interactions in young adults with type 1 diabetes, and e-health strategies that have shown promise for some chronic illnesses outside of type 1 diabetes [270, 361].

There is, however, a clear need for standardised flexible-hours CSII-related support, which was seen by healthcare professions as currently inadequate (chapters 5 and 7). Across Australia there are numerous non-type 1 diabetes specific after-hours telephone health support services available. For example, a Nurse on Call service for general health concerns is available in Victoria [362], whereas the Rural link service provides after hours' mental health telephone support for people in rural communities in Western Australia [363]. Similarly, the Australian Government-funded Health Direct Australia telephone service provides after hours' access to a general practitioner [364]. An Australian-based diabetes educator service is required to provide timely assistance for diabetes-related matters, to determine the need for and potentially prevent unnecessary use of acute healthcare hospital services. This could also include coverage for those not utilising CSII therapy as their method of insulin delivery. The availability of after-hours mobile phone support, for example, has been associated with reduced progression of ketosis to diabetic ketoacidosis in young adults with type 1 diabetes in New South Wales, despite poor diabetes control [365].

5. Better service monitoring

Improved national monitoring of type 1 diabetes vascular complications would help assess the impact of service reconfiguration and/or alteration in service delivery, to ultimately improve the outcomes of young adults with type 1 diabetes. The recently formed collaborative Australian Diabetes Data Network Registry [366, 367], which involves participating diabetes healthcare services uploading data to the Network every six months, can presently report from diagnosis of type 1 diabetes as a child through to transition to adult treatment and will therefore be able to provide data and reports in the future. Expansion of the data registry could include healthcare services for people with type 1 diabetes diagnosed in adulthood. Further national monitoring of type 1 diabetes disease complications could be undertaken through coordination of general practice, through national structures analogous to the Primary Health Networks of New South Wales. The development and progression of type 1 diabetes disease complications could be made notifiable as core service key performance indicators, on a par with other indicators such as unplanned readmission to the same or another public sector acute healthcare service unit within 28 days of discharge [368].

6. Policy development

A leading reason for the burden experienced by healthcare professionals was the absence of consensus or definition for some key organisational processes, both within and between services. Dissemination and adoption of recent Australian evidence-based CSII therapy guidelines [97], and formulation of guidelines relating to CGM will assist in improving the equity of healthcare around use of these insulin delivery and blood glucose monitoring technologies. This should also facilitate delivery of evidence-based healthcare in these topic areas and hence reduce the burden and risk of healthcare

professional disengagement (chapters 5 and 7). Local policies and procedures to translate these guidelines into practice will, however, need to be formulated.

Policies and procedures to translate guidelines into practice should consider factors such as the appropriate selection of patients for CSII use and self-management, the role of patients in choosing insulin delivery and blood glucose monitoring systems, and levels of healthcare service staffing required [10, 96, 97]. The additional time required to provide technology-based healthcare has been highlighted, and the consequent reduction in time available to other patients (chapter 7). The healthcare professional time required to establish a patient as a CSII user, largely from nurses, has been reported as median 18.6 hours with 14.1 interactions over 11.8 weeks [98]. Considering diabetes educators in Australia are reported to spend around 50% of their day on patient education; 20% on administration; and 30% equally distributed between research, quality improvement, staff education and other duties, such a large number of interactions will greatly impact their workload [309]. Lack of availability of the healthcare professional time needed for establishment of a new CSII user has also been cited as a reason for the low prevalence of CSII use in the United Kingdom, which falls well below the expectation of the National Institute for Health and Care Excellence, and use in other countries [141, 143-145, 369].

Consideration also needs to be given to the expertise required by healthcare professionals to care for CSII and CGM users, and to support other staff. Australian consensus guidelines around CSII highlight the need for involvement of a skilled multi-disciplinary healthcare team [97]. However, there is no stipulation or consensus as to the level of expertise required. Many healthcare services also do not require further

training or certification by staff caring for people with type 1 diabetes using these technologies. To realise the potential benefits of insulin delivery and blood glucose monitoring technologies, the level of expertise required needs to be defined. Many healthcare professionals may need to be educated to attain and retain the skills required to deliver expert care.

7. Support of healthcare professionals

Knowledge deficits were also identified as barriers to provision of expert support. Rotating clinical placements across and between paediatric and adult diabetes care settings could assist in improving healthcare professional expertise, with paediatric experience and the greater exposure to technology this entails shown to be influential in diabetes educators' intentions and use of common diabetes-related technologies (chapter 6). To align diabetes educators' technology intentions with their delivery in practice, their confidence and competence, preparation (intentions and training) and perceived ease of use, are all important elements (chapter 6), and may be targeted as part of routine continuing professional development. Subjective norms and perceived contribution to improving clinical practice were also shown as influential (chapter 6); both could perhaps be addressed locally through, for example, evidence based workshops led by respected opinion leaders.

External stakeholders such as the Australia Diabetes Educators Association, the leading Australian organisation for multi-disciplinary healthcare professionals who provide diabetes education and care, also have an important role to play in education. They may be able to promote and facilitate mentorship around technology use (chapters 6 and 7), through their established member mentoring program [323], and through providing

periodic detailed summaries of evolving CSII and CGM systems, to help members keep up to date (chapter 7). The Australian Diabetes Educators Association also provide modules to enhance members' knowledge around some diabetes-related common technologies [370]. Their completion could be become a requirement to assist with attaining and retaining the status of credentialled diabetes educator. The need for ongoing support for healthcare professionals is particularly pressing considering technology evolution and increasing uptake.

8. Increased availability of insulin delivery technologies

Pending the availability and capacity of diabetes healthcare services equipped to competently provide CSII-related care, with policies and procedures in place to support this, there are opportunities to better facilitate and empower some young adults with type 1 diabetes to self-manage their disease through wider use of insulin delivery technologies. The Australian Government has recognised the importance of supporting equity of access to CSII technology for disadvantaged children through the Type 1 Diabetes Insulin Pump Program [149]. In this program, the sum of $6,400 (or 80% of the device cost) may be available to persons with type 1 diabetes aged under 18 years that have an annual family income under $73,146 or receive Centrelink income support payments; varying support with the 20% co-payment is available for those that qualify for the maximum device subsidy. Policy innovation maybe required to enable equitable CSII access, as is the case in Ontario, Canada, for example, where a CSII device may be provided for patients with type 1 diabetes regardless of age [147, 148]. However, only a small proportion of CSII users in Australia obtain access to insulin delivery technology through the Australian Government's Type 1 Diabetes Insulin Pump Program [149]. The majority (89%) of CSII users in Australia receive some form of financial assistance

to acquire their device, with almost all (97%) using private health insurance [141]. The consequence of the private insurance method of purchase is that usage is more commonplace in higher socio-economic areas (14% versus 6%) [141]. Given the complex nature of patterns of socioeconomic advantage and disadvantage amongst the community, increased financial support alone might exacerbate rather than ameliorate inequalities between those who can afford to use CSII and those who cannot.

9. Increased capacity for use of communication technologies

There are also opportunities to promote engagement of young adults with type 1 diabetes with diabetes healthcare services through increased capacity to use communication technologies. Increased use of communication technologies, particularly in the form of video-conferencing, could facilitate a more flexible and responsive health system to enable targeted care, the provision of peer support amongst diabetes healthcare professionals, cross-coverage from areas where technology expertise exists, and professional development where applicable [176]. Young adults with type 1 diabetes in rural localities of New South Wales have reported valuing face-to-face service [254] and therefore increased use of video-conferencing may be more desirable to promote communication and engagement. Video-conferencing has been the means through which some young people with type 1 diabetes in Australia have re-engaged with specialist diabetes healthcare services [175], and it can be utilised at relatively low cost.

Many healthcare professionals in regional, rural and remote localities who had found the cost of video-conferencing systems prohibitive were still able to provide support to patients with type 1 diabetes using free, patient-friendly personal communication

software such as (currently) Skype™ and Facetime® (chapter 7). The use of Skype™, for example, may improve clinical control in patients with type 1 diabetes similar to regular clinic visits [371], and has improved outcomes in other chronic diseases such as Chronic Obstructive Pulmonary Disease [372]. Though there are concerns about the security of providing healthcare support through use of personal communication software, increased access to video-conferencing technology through such platforms should be explored. The Royal Australian College of General Practitioners have released a statement indicating that there is currently no clear evidence to suggest that Skype™ is unsuitable for clinical use [373].

There are also opportunities for increased use of apps, as adjuncts to type 1 diabetes self-management, allowing transfer of digital information through use of physical or 'wireless' connections between separate geographic locations. Diabetes educators reported difficulty in keeping up to date with apps, because of their increasing numbers and the workload burden this represents (chapter 7). The Australian Diabetes Educators Association may also be able to provide periodic detailed summaries of available apps, to help members keep up to date.

Many factors outside of the direct control of healthcare services may, however, need to be addressed to enable increased utilisation of communication technologies. A key issue is internet network coverage, reported by diabetes educators in non-metropolitan areas as often erratic, especially outside of school hours, resulting in inconsistent visual and sound quality which often deterred use (chapter 7). Improvements in coverage are required, which are expected to occur through the Australian Government National Broadband Network; an Australian telecommunications infrastructure project [374].

However, the rollout of related infrastructure was initially planned to reach only approximately 93% of premises in Australia by June 2021 and this is therefore not a panacea, especially when young adults with type 1 diabetes in rural or remote areas of Australia currently have limited access to adult diabetes healthcare services. The increased utilisation of communication technologies to promote diabetes healthcare service engagement is a limited contribution rather than a full solution to improve the health outcomes of young adults with type 1 diabetes in Australia, and their engagement with adult-based diabetes healthcare services. Regardless of any changes made to diabetes healthcare service configuration and delivery, there is a need for improved monitoring to help determine progress and cost effectiveness [375].

In summary, many interacting factors both intrinsic and external to the young adulthood developmental life stage can limit type 1 diabetes self-management and sustained engagement with diabetes healthcare services, increasing the risk of premature morbidity and mortality in this population. This thesis has identified numerous opportunities to improve diabetes self-management in young adults with type 1 diabetes, and their communication and engagement with adult-based diabetes healthcare services in Australia.

Strengths and limitations of the work as a whole

This thesis has provided depth and detail on the little explored topic of the current state and future opportunities to better support young adults with type 1 diabetes in Australia, using both quantitative and qualitative research methods. Strengths of the thesis partly lie with its original contributions to the field.

Firstly, the thesis incorporates the first published systematic review and Australian data of vascular complications (retinopathy, nephropathy and/or hypertension) and factors predicting their development in this important population. Secondly, the thesis has provided valuable Australian data on the attitudes, perceptions and everyday experiences of diabetes management amongst young Australians using CSII technology, and their intentions towards CSII use once they become adults; information of value for diabetes healthcare service planning. The thesis also incorporates the first published study of the intended and reported professional use, and factors predictive of use, of common diabetes-related technologies by diabetes educators across Australia, for patients with type 1 diabetes. This involved an adapted and validated version of a survey instrument based on the TAM [300-305], suitable for exploration of technology use in healthcare environments. Finally, the thesis incorporates the first published in-depth study which identified the perceived experiences, supports and barriers to use of common diabetes-related technologies by diabetes educators across Australia, for people with type 1 diabetes.

The thesis has considered the current state and future Australian services to support young adults with type 1 diabetes from multiple angles, across diverse and wide sociological and geographical areas. Much of the data obtained derived from large cohorts, from either one local health district, enabling in-depth exploration, or Australia-wide. Where appropriate, consideration was given to the experiences of similar healthcare systems internationally. In light of the literature already available, the thesis used this source rather than collect new data to represent the views of health

consumers, especially the perspectives of young adults with type 1 diabetes towards future Australian adult-based diabetes healthcare services.

The care of young adults with type 1 diabetes is not achieving the priority it warrants in Australia; thesis findings support the need for change. The option to appoint a Minister for young people was recently turned down by the Australian Government, despite the linkage of care of young adults to the Australian National Strategic Framework for Child and Youth Health [51] and international statements [7, 338]. This decision warrants reconsideration. The financial impact of type 1 diabetes has been documented [29-32], and though the thesis does not explicitly focus on economic analysis, it does indicate where savings can be made by a focus on funding prevention rather than acute service crisis management. Specialist diabetes healthcare services (including their managers), managers of healthcare organisations, policy-makers and external stakeholders need to be persuaded to better support young adults with type 1 diabetes through age-relevant diabetes healthcare services, especially outside metropolitan areas.

CHAPTER 9. CONCLUSION AND RECOMMENDATIONS

In conclusion, this thesis demonstrates that considerable numbers of young adults with type 1 diabetes in Australia are affected by vascular complications (chapters 2 and 3). The support of healthcare services is then crucial to afford the greatest chance to support type 1 diabetes self-management, and early complication detection, treatment initiation, regular monitoring and secondary prevention. However, regular contact with diabetes healthcare services does not always occur reliably, with evidence of low attendance for routine preventative health services and high unplanned use of acute services (chapters 3 and 4). Consequently, greater understanding is required how diabetes healthcare services can be reconfigured or delivered differently, especially in regional, rural and remote areas, to meet the needs of young adults with type 1 diabetes and achieve better outcomes.

Technology has an important role in facilitating and empowering young adults with type 1 diabetes to self-manage their disease and to communicate and engage with diabetes healthcare services, both routinely and as required. However, the reality of healthcare service delivery is that the needs of young adults with type 1 diabetes are often not met, particularly in relation to CSII. The needs of healthcare professionals providing care around use of common diabetes-related technologies are also often not met either.

Diabetes healthcare professionals deliver a complex role in providing support for patients with type 1 diabetes using insulin delivery, blood glucose monitoring and communication technologies across diverse contexts (chapters 5 and 7). Factors common across studies included difficulties with access, service incoordination and

insufficient range of healthcare professional expertise; all are amenable to change. Difficulties were encountered by some patients with type 1 diabetes around access to expert diabetes healthcare, when considering use of insulin delivery and blood glucose monitoring technologies. Many healthcare professionals also had limited support. Further, some patients with type 1 diabetes and healthcare professionals experienced difficulty with access to particular common diabetes-related technologies. Service co-ordination, however, was undermined by lack of common data systems, communication infrastructure and connectivity, and an absence of consensus or definition for some key organisational processes, particularly when considering CSII. Fragmented and inconsistent care also reflected lack of specific expertise in some locations, considered essential to support CSII use particularly.

In summary, this thesis provides an insight into Australian healthcare services for young adults with type 1 diabetes. In this age group, vascular complications were demonstrated to occur frequently, as do acute hospital presentations and admissions for diabetes crisis management. For many young adults, specialist diabetes services including secondary prevention are inaccessible, under-utilised or inadequate for purpose. Policy and practice innovation is required to assist individual clinicians, specialist diabetes healthcare services (including their managers), policy-makers, managers of healthcare organisations and external stakeholders, to better support young adults with type 1 diabetes, especially outside metropolitan areas.

The need for consistent, coordinated and age-relevant care, and the infrastructure to support this presents an opportunity to drive integration of care and team-working across as well as within disciplines and settings. This could be facilitated by

reconfiguration of multidisciplinary teams and appropriate resource apportionment where necessary, with the supported use of common diabetes-related technologies as a focus. Diabetes technologies are advancing rapidly, requiring a skilled and responsive workforce and flexible health services capable of adapting rapidly to change. The need for change is particularly pressing and unless this is made, the development and progression of vascular complications in young adults with type 1 diabetes, low attendance for routine preventative health services and high unplanned use of acute healthcare services by this population will continue.

Recommendations

1. The potential for dedicated type 1 diabetes healthcare services for adolescents and young adults should be explored, on the basis that current medical systems are arranged separately and differently around children to those for adults; an arrangement which serves young adults poorly. This however does not eliminate transition issues. The components of effective structured transition between medical systems in Australia should be further explored and policy established, on the basis that this will help improve the readiness for transition.

2. The components of adult-diabetes healthcare service reconfiguration should be explored, including for CSII-users. This should consider the development of new models of care to support regional, rural and remote young adults with type 1 diabetes, and the development of new funding models that cost-shift to promote expansion of preventive care, on the basis that this may recoup some of the expense of acute healthcare service type 1 diabetes crisis management. CSII users need dedicated services for related care, and for after-hours support.

Ultimately change may improve healthcare service equity and delivery, and health outcomes.

3. The use of Australian Government financial incentives available to healthcare professionals should be further explored, on the basis that this will help to promote diabetes healthcare contact with young adults with type 1 diabetes. Australian Government Medicare rebates should be considered for availability to credentialled diabetes educators, and the use of healthcare professional pay-for-performance incentives.

4. The potential to reduce the quantity of disposable insulin pens and pen-fill cartridges that can be prescribed by physicians and Nurse Practitioners, especially in acute healthcare services, and the availability of insulin without the need for a prescription should be explored. Further, conditions should be applied to access to Australian Government subsidised CSII and CGM consumables, incentivising a defined minimum level of contact with authorised specialist diabetes healthcare professionals (such as an endocrinologist and credentialled diabetes educator) per year. Collectively change will help promote the contact of patients with type 1 diabetes with diabetes healthcare services. The potential for conditions to also be applied to Australian Government subsidised blood glucose testing strips, incentivising a defined minimum level of contact, should also be explored.

5. Comprehensive national monitoring of type 1 diabetes disease complications should be undertaken, on the basis that this will help measure the impact of and

need for change to diabetes healthcare provision, both locally and nationally. Expansion of the Australian Diabetes Data Network Registry [366, 367] could include healthcare services for people with type 1 diabetes diagnosed in adulthood. Further national monitoring of type 1 diabetes disease complications could be undertaken through coordination of general practice, through national structures analogous to the Primary Health Networks of New South Wales. The development and progression of type 1 diabetes disease complications could be made notifiable as core service key performance indicators.

6. Recent Australian evidence-based CSII therapy guidelines [97] should be disseminated and adopted, and guidelines relating to CGM formulated, as this will assist in improving the equity of care around use of these insulin delivery and blood glucose monitoring technologies. Guidelines may also reduce the risk of healthcare professionals' disengaging in these aspects of care. Policies and procedures to translate guidelines into practice, however, need to be formulated.

7. The expertise required by healthcare professionals around use of CSII and CGM technologies should be defined, with certification by healthcare professionals being a requirement of healthcare services, for them to provide related-care to people with type 1 diabetes. While this may reduce the number of healthcare professionals providing CSII and CGM care, a defined level of expertise will facilitate equity of service delivery, enable professional development of competent healthcare professionals around use of these insulin delivery and blood glucose monitoring technologies, and facilitate support of other staff.

Rotating clinical placements across and between paediatric and adult diabetes care settings should become mandatory as part of diabetes healthcare system employment, on the basis that this could assist in improving healthcare professional expertise. Diabetes educators' confidence and competence, preparation (intentions and training) perceived ease of technology use, subjective norms and perceived contribution of technology to improving clinical practice should be routinely targeted as part of continuing professional development. Further, the Australian Diabetes Educators Association provide modules to enhance members' knowledge around some diabetes-related common technologies [370], and their completion should be become a requirement to assist with attaining and retaining the status of credentialled diabetes educator.

8. The potential to increase the Australian Government CSII subsidy for low income families with children with type 1 diabetes, to cover low income young adults should be explored. Improved access to this technology by young adults with type 1 diabetes will afford the potential to improve health-related outcomes, offering easier and more precise insulin dosing, and greater flexibility via instant adjustments to the infusion to allow for variations in dietary intake, exercise or illness.

9. The availability of video-conferencing technology should be maximised on the basis that use may allow for a more flexible and responsive health system to enable targeted healthcare. Diabetes healthcare services should be routinely equipped with personal communication software such as (currently) Skype™,

Facetime® and Messenger™, and have contact addresses provided. Adequate internet coverage should be available.

Future research

Thesis findings indicate that there is a need for future research to better determine how young adults with type 1 diabetes can be better supported by Australian healthcare services. A primary focus should be on the potential for dedicated diabetes healthcare services for adolescents and young adults with type 1 diabetes, in addition to models of transition to prepare young people with type 1 diabetes for, and to support them with disease self-management as they access adult-based diabetes healthcare. Young people's positive attitudes and perceptions of their self-efficacy and diabetes management had, for example, been highlighted in the survey of young people with type 1 diabetes and their parents (chapter 4). Though retention in adult-based healthcare has been reported to be higher with a comprehensive transition program compared with standard practice [63], the elements that should form part of this specific to Australia remain unclear. The issue of bridging separate models and systems of care may have positive implications for a wide spectrum of other diseases.

Future research should also focus on the use of financial incentives to promote diabetes healthcare professional contact with young adults with type 1 diabetes. Consideration also needs to be given to the development of new models of care to support regional, rural and remote young adults with type 1 diabetes, and funding models that cost-shift to promote expansion of preventive care, on the basis that this may recoup some of the expense of acute healthcare service type 1 diabetes crisis management. Attention should

be given to the support available to young adults around mental health, and the provision of diabetes-related medications, glucose and ketone-monitoring supplies, aspects which were either briefly or not considered in this thesis. This is to reveal and ultimately utilise any opportunities to make improvements.

There is a need to better determine how diabetes healthcare services can better integrate care and improve team-working across as well as within settings and disciplines, to utilise innovative healthcare approaches and make much better and more flexible use of communication technologies. Consideration should also be given to device and consumable provision, and updates to both young adults with type 1 diabetes and healthcare professionals providing related care, to achieve the anticipated benefits for the entire period of technology use.

Finally, economic analysis is required to help determine the level of efficiency and effectiveness of proposed models of care. Such data will provide evidence based information to local health districts and the Australian Government to assist in their funding decisions, with the dual aim of achieving a cost-effective allocation of resources and the greatest benefit for patients with type 1 diabetes.

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APPENDIX

Appendix 1: Published paper

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BMC Research Notes

RESEARCH ARTICLE Open Access

Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes: systematic literature review

Steven James[1*], Robyn Gallagher[2], Janet Dunbabin[3] and Lin Perry[4]

Abstract

Background: Vascular complications curtail life expectancy and quality of life in type 1 diabetes and development at younger ages is particularly detrimental. To date no review has summarised the prevalence or factors predicting their development in young adults.

Methods: A quantitative epidemiological systematic review was conducted to identify the prevalence and predictive factors for development of retinopathy, nephropathy and hypertension in young adults (sample age mean [plus 1SD] 18–30 years) with type 1 diabetes, using processes adapted from established review methods set out by the Centre for Reviews and Dissemination.
MEDLINE (Ovid), Scopus (Elsevier), CINAHL, Science Direct (Elsevier), Google Scholar and Cochrane databases were searched to identify relevant articles published between 1993 and June 2014. From this eleven papers were retrieved, appraised and results summarised by three reviewers using established methods.

Results: Some form of retinopathy occurred in up to almost half of participants; more severe forms affected up to one in ten. One in six was reported with microalbuminuria; one in 14 had macroalbuminuria. Hypertension occurred in almost one in two participants. Applying out-dated high thresholds this decreased to approximately one in ten participants. Glycaemic control was a consistent predictor of vascular disease in this age group.

Conclusion: Prevalence rates of retinopathy, nephropathy and hypertension in young adults with type 1 diabetes emphasise the importance of regular complication screening for early detection and treatment. The predictive effect of glycaemic control reinforces its importance for prevention of vascular complications.

Keywords: Quantitative epidemiological systematic review, Vascular complications, Prevalence, Predictors, Retinopathy, Nephropathy, Hypertension, Young adults, Type 1 diabetes

Background

The increasing incidence of type 1 diabetes in many countries challenges health systems because the disease is presently incurable with no known method of prevention [1]. Around 490,100 children live with the disease worldwide, with incidence estimated to be increasing in children under 15 years by 2.8% per year [1,2]. This trend is particularly worrying because type 1 diabetes increases mortality and morbidity population-wide, including in young adults [3-5]. People with type 1 diabetes diagnosed before the age of 30 years have been calculated to have a 4.7-fold excess mortality risk [6].

Vascular complications are often the cause of this early mortality. However, there is currently little information available about the prevalence or predictive factors for development of vascular complications of type 1 diabetes among young adults. Identification of disease complication prevalence and any predictive characteristics will establish a benchmark of these risk factors, and may assist healthcare professionals to target appropriate information and support with the aim of deferring or averting their onset.

The development of vascular disease in type 1 diabetes has been proposed as a consequence of disordered activity

* Correspondence: Steven.B.James-1@student.uts.edu.au
[1]Huntsville District Memorial Hospital, Muskoka Algonquin Healthcare, 100 Frank Miller Drive, Huntsville, Ontario P1H 1H7, Canada
Full list of author information is available at the end of the article

of lipid metabolism enzymes or transporters affecting endothelial function, inflammation, coagulation, platelet activation and fibrinolysis [7]. In combination with population-wide cardiovascular and athero-thrombosis risk factors, a state of persistent and progressive damage to the vascular wall (macro-angiopathy) is created [8]. Micro-angiopathic disease also occurs, with hyperglycaemia a leading pathogenic factor [9]. Vascular co-morbid diseases include retinopathy, which may cause reduced vision and blindness, and nephropathy, which may result in renal failure and require dialysis or kidney transplantation. This is in addition to hypertension, which is linked to peripheral, cardio- and cerebrovascular disease, the end points of which are limb amputations, cardiac failure, stroke and sudden death. As vascular complications curtail both life expectancy and quality of life [10], development at younger ages when people are typically establishing careers and families is particularly detrimental.

Young adults may be particularly vulnerable to complications because many have unique health needs relating to their psychological, physical and socio-cultural life stage issues; these commonly lie outside health services' remit and place them at high risk for poor self-management. Diabetes services are predominantly structured into exclusive paediatric and adult services, with transition between these services not clearly the responsibility of either: an arrangement which serves young adults poorly. This transition stage was first formally identified as challenging by Blum et al. [11], however, decades later similar levels of difficulty with the transition process are still being reported [12]. Consequently, young adults with type 1 diabetes may not adhere to diabetes regimes, and may disengage from diabetes services after transition [13,14]. Attrition from, or failure to engage with, diabetes services as an adult too-frequently results in reduced diabetes self-management and well-being, and inadequate screening for complications.

The potential benefits of models of transition to maintain engagement with adult diabetes services post-transfer from paediatric care have been flagged, and characteristics associated with reduced attrition and increased satisfaction and successful service redesign described [15-17]. However, the effect of transition service redesign has not been examined in terms of outcomes such as onset of vascular complications; neither has there been any attempt to summate or quantify the degree of complication-related morbidity and early mortality experienced by this young adult group. Lack of international benchmarks limits evaluation and deters appropriate prioritisation of service redesign to promote retention of young adults in contact with services, an essential element in achieving good glycaemic control to defer onset of complications [18-20].

The aim of this review was to identify the prevalence and factors predictive of development of vascular complications (retinopathy, nephropathy and hypertension) occurring in young adults with type 1 diabetes. For the purpose of this review, the term young adult refers to ages 18–30 years inclusive.

Methods

A quantitative epidemiological systematic review was conducted using processes adapted from established review methods set out by the Centre for Reviews and Dissemination [21]. Standards derived from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) were applied [22]. The review protocol is available from the authors on request.

Outcome definitions and recommended measurement methods

Definitions and criteria for 'best practice' screening methods for retinopathy, nephropathy and hypertension were sought. Detailed recommendations were available in American, Canadian and British guidelines [23-25]:

Diabetic retinopathy

The presence and characteristic evolution of typical retinal microvascular lesions in an individual with diabetes. Besides micro-aneurysms, blood vessel changes include intra-retinal haemorrhage, and vascular tortuosity and malformation (non-proliferative retinopathy) leading to abnormal vessel development (proliferative retinopathy). Seven-standard field stereoscopic-colour fundus photography with interpretation by a trained reader is the recommended standard screening for diabetic retinopathy, though direct ophthalmoscopy or indirect slit-lamp fundoscopy through dilated pupil or digital fundus photography may also be used. Treatment with laser photocoagulation surgery prevents vision loss [26-29]. The Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [24] advocates that screening should be undertaken at least annually. However, the American Diabetes Association [23] advocates consideration of lesser frequency (every two - three years) following one or more normal eye examinations.

Nephropathy

A glomerular filtration rate (GFR) less than 60 mL/min present for three or more months, or any evidence of kidney damage for three or more months regardless of GFR [30]. In addition to any anatomical or pathological abnormalities or glomerular haematuria, it can be revealed by micro- or macroalbuminuria/proteinuria. Screening for nephropathy in adults with diabetes entails estimation of the level of kidney function and assessment of urinary albumin excretion. Significantly reduced kidney function is evidenced by an estimated GFR less than 60 mL/min; serum creatinine should be used to estimate GFR and stage the level of chronic kidney disease. Albuminuria should be

determined through a timed/24-hour collection, or through a random spot test to determine albumin to creatinine ratio (ACR). The measurement of a spot urine for albumin, without simultaneously measuring urine creatinine, is susceptible to false negative/positive determinations.

Microalbuminuria was identified as urinary albumin excretion of either 30–299 or 300 mg/day in a 24-hour urine collection, with variations based on differing guidelines [23,24], or an ACR of 2.0 - 20.0 mg/mmol. Macroalbuminuria (overt nephropathy) was identified as 300 mg/day or above if a 24-hour urine collection was performed, or an ACR of greater than 20.0 mg/mmol.

Blood pressure

Recommended targets are less than 130/80 mmHg for people with diabetes. Measurement of blood pressure should be undertaken by trained personnel, with participants in the seated position with feet on the floor and arm supported at heart level, after five minutes of rest. Cuff size must be appropriate for the arm circumference, with elevated values confirmed on a separate day. The American Diabetes Association [23] advocate that blood pressure should be measured at every routine visit.

Literature search methods

MEDLINE (Ovid) and Scopus (which incorporates Embase journals), CINAHL, Science Direct (Elsevier), Google Scholar and Cochrane were searched by the first author to June 2014 to identify relevant articles. The MESH headings 'Diabetes Mellitus, Type 1'; 'Diabetic Retinopathy'; 'Diabetic Nephropathies'; 'Hypertension'; 'Prevalence'; 'Cross-sectional Studies'; and 'Prospective Studies,' and keywords 'Type 1 diabetes'; 'Insulin Dependent Diabetes Mellitus'; 'Juvenile Onset Diabetes Mellitus'; 'Retinopathy'; 'Eye Diseases'; 'Nephropathy'; 'Kidney Diseases'; 'High Blood Pressure'; and Longitudinal Studies' were used. The full search strategy can be viewed in Additional file 1. In addition, reference lists of all eligible studies were handsearched.

Inclusion criteria were:

- Samples with type 1 diabetes;
- Mean age (plus 1SD) 18–30 years, or where the results for this age range were reported separately from other age groups; and
- English language studies only due to lack of resources for translation.

Exclusion criteria:

- Studies reporting data collected pre 1993 as from this date the definitive Diabetes Control and Complications Trial [9] established that the onset and progression of micro-vascular complications can be significantly reduced by HbA1c management. This changed diabetes management to make glycaemic control central, and hence management and complication rates may have changed.

Search outcome

A total of 7,740 records were identified, downloaded to EndNote version X4 and screened by reading titles and abstracts. Of these, 7,601 records were excluded as duplicates or not meeting review inclusion criteria, including 12 non-English language papers. The remaining 139 full-text articles were assessed for eligibility; their reference lists were searched and an additional 12 papers identified. Of these 151 papers, 140 did not meet review inclusion criteria, leaving eleven relevant papers [31-41]. The search process and outcomes are summarised in Figure 1.

Quality appraisal

With no universally accepted 'gold standard' method for evaluating and interpreting epidemiological study quality [42], to determine the strength of evidence quality appraisal was undertaken using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) [43] checklist for cohort, case-control, and cross-sectional studies. Eligible papers were also evaluated for methods of assessment and measurement of retinopathy, nephropathy and hypertension in relation to current evidence-based guideline recommendations. This appraisal can be viewed in Additional file 2. To ensure reliability in data extraction and quality appraisal, a sample of papers included in the review were independently appraised and data extraction compared by the second and last authors (six papers each). Agreement was reached for all papers.

Data extraction and synthesis

Data were extracted to a purpose-designed spread-sheet in Microsoft Office Excel based on relevant elements of the Consolidated Standards of Reporting Trials (CONSORT) checklist [44]. Extracted data can be viewed in Table 1 and Additional file 3. The number of diabetes centres involved in each study was noted to aid interpretation of transferability of findings.

Results

The eleven papers derived from nine separate studies and mainly employed cross-sectional research designs; three papers that had provided data applicable to the target age group had involved a 1995 cohort of a Danish nationwide longitudinal study [32,37,38]. Data were collected via case note audit in three studies, and via documentation surveys in two further studies. Only three of the eleven studies solely provided data relating to the

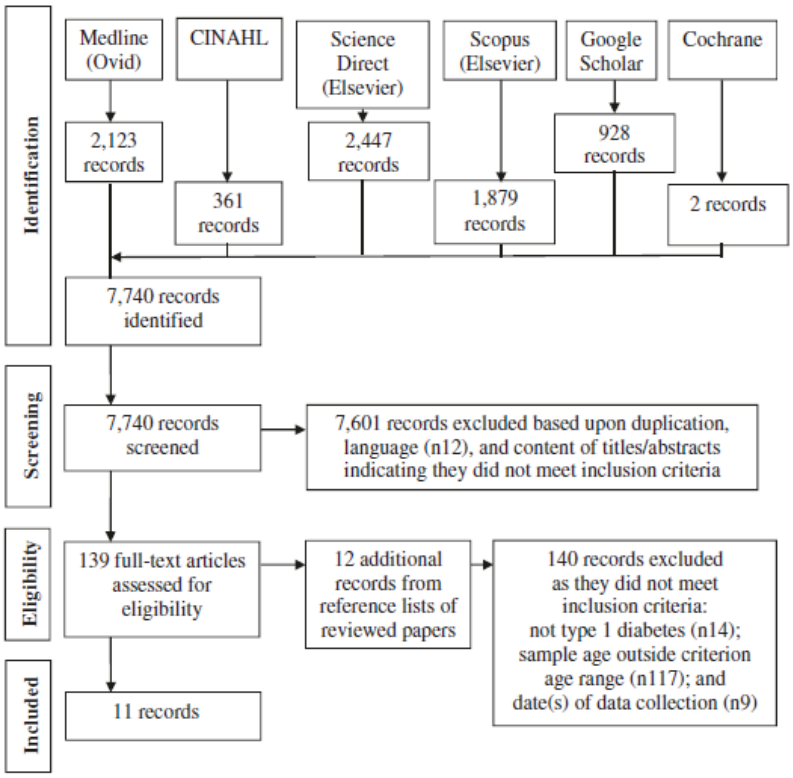

Figure 1 Literature search and review flow chart.

target population; all varied in their methodological quality and are summarised in Table 1 and Additional files 2 and 3. Ethnicity was reported in only three papers, and only one study focused on rural/non-urban populations or localities.

Prevalence and prediction of retinopathy

The prevalence of diabetic retinopathy in the target population was reported in seven papers [31,32,34,36-38,40]. Prevalence data were reported for 215 applicable participants by Arfken et al. [31], for both 95 (2010) and 85 (2011) participants by James et al. [34], and 53 by Salardi et al. [40]. In longitudinal studies data were also reported on 324 applicable participants by Broe et al. [32], on 290 at nine years diabetes duration by LeCaire et al. [36], on 190 by Olsen et al. [37], and on 353 by Olsen et al. [38]. These two latter papers reported data from 19 paediatric departments (both) and five/six departments of internal medicine, whereas Salardi et al. [40] reported data from eleven centres; the other four papers did not provide detail.

Retinopathy was assessed and measured according to current best practice guideline recommendations in all papers. In these seven studies from four different countries with participants sampled by different methods, retinopathy prevalence varied somewhat (Table 1). Salardi et al. [40] reported an overall prevalence of 40%, with 27% and 88% at less than or greater than 20 years diabetes duration, respectively, whereas James et al. [34] reported a prevalence of 13.7% and 9.4%, and Olsen et al. [38] 57.6%; LeCaire et al. [36] reported 47% with retinopathy at nine years diabetes duration (6% - 73% with retinopathy at mean ages 19.5 - 24.8 years). At similar diabetes duration proliferative or treated diabetic retinopathy was reported in 10.2% of participants by Arfken et al. [31], but affected 0.3% of those at nine years diabetes duration by LeCaire et al. [36]; Broe et al. [32] reported a prevalence of proliferative retinopathy of 0.5% - 0.7%.

Data were provided relating to predictors of diabetic retinopathy in the target population in only two of these studies. Arfken et al. [31] reported that in White participants, a strong association was demonstrated between the development of proliferative retinopathy and existing moderate/severe diabetic retinopathy (Odds Ratio (OR) 16.55 (95% Confidence Interval (CI) 5.43 - 50.45)). Glycaemic control was also shown to be significant (2% change in HbA1c; OR 2.17 (95% CI 1.34 - 3.50)). This

Table 1 Reported prevalence of diabetic retinopathy

Author(s); country of origin	Number of centres	Age, mean (SD) yrs.; sample size	Any DR	Non-proliferative DR	Proliferative or treated DR	Predictors
Arfken et al. 1998; U.S.A. [31]	Not provided	19.0 (11.0) (White); n 215 (n 312 TS)			10.2%	Moderate/severe DR (proliferative DR) OR 12.40 (* 5.31 - 28.98) Moderate/severe DR in White participants (proliferative DR) OR 16.55 (* 5.43 - 50.45) HbA1c (2% change) (proliferative DR) OR 1.92 (* 1.36 - 2.70) HbA1c (2% change) in White participants (proliferative DR) OR 2.17 (* 1.34 - 3.50)
Broe et al. 2014; Denmark [32]	Not provided	21.0 (3.3) (In 1995 study), 20.2 (3.2) (Not in 1995 study); n 185 (In 1995 study), n 139 (Not in 1995 study) (n 324 TS)		In 1995 study: 61.2% Not in 1995 study: 51.8%	In 1995 study: 0.5% Not in 1995 study: 0.7%	
James et al. 2014; Australia [34]	Not provided	23.0 (3.7); n 95 (2010), n 85 (2011) (n 707 TS)	2010: 13.7% 2011: 9.4%			
LeCaire et al. 2006; U.S.A. [36]	Not provided	9 yrs.: 18.8 (7.2) (DR -), 21.1 (6.4) (DR +); n 290 (n 474 TS)	9 yrs.: 47%	9 yrs.: 33% (Min); 11% (M); 2% (Mod - Sev)	9 yrs.: 0.3%	Age at examination (per year) (DR) < 20 years Hazard ratio 1.2 (* 1.1 - 1.3) ≥ 20 years Hazard ratio 1.0 (* 1.0 - 1.0) Diabetes duration at examination versus 4 years (DR) 7 years Hazard ratio 1.6 (* 0.8 - 3.3) 9 years Hazard ratio 4.1 (* 2.2 - 7.6) 14 years Hazard ratio 7.9 (* 3.5 - 17.5) Non -White-race (versus White race)

Table 1 Reported prevalence of diabetic retinopathy *(Continued)*

					Hazard ratio 1.6 (* 0.8 - 3.0) HbA1c (per 1%) by diabetes duration (DR) 4 years Hazard ratio 1.1 (* 1.0 - 1.3) 7 years Hazard ratio 1.4 (* 1.3 - 1.6) 9 years Hazard ratio 1.4 (* 1.2 - 1.6) 14 years Hazard ratio 1.2 (* 1.0 - 1.6) Male sex (DR) Hazard ratio 1.3 (* 1.0 - 1.7)
Olsen et al. 1999; Denmark [37]	19 and five^	Median 21.1 (range 12.0 - 26.9); n 205 > 20 yrs. (n 339 TS)		48.9% (Min) 20% (Mod plus)	
Olsen et al. 2004; Denmark [38]	19 and six^	20.4 (3.2) (Prepubertal diabetes onset), 24.2 (1.3) (Pubertal/post-pubertal diabetes onset); n 304 (Prepubertal diabetes onset), n 49 (Pubertal/post-pubertal diabetes onset) (n 353 TS)	57.6%		HbA1c (DR); $p < 0.0001$ Diabetes duration before puberty (DR); $p < 0.05$ after the onset of puberty (DR); $p < 0.001$
Salardi et al. 2012; Italy [40]	n 11	Very young pre-pubertal onset 22.0 (4.5); n 53 (n 105 TS)	40% Diabetes duration - < 20 yrs.: 27% > 20 yrs.: 88%	30% (M); 10% (Mod - Sev)	

(DR) Diabetic retinopathy (M) Mild (Min) Minimal (Mod) Moderate (n) Number (OR) Odds ratio (Sev) Severe (SD) Standard deviation.
(TS) Total sample (*) 95% Confidence interval (^) 19 paediatric departments and five/six departments of internal medicine.

latter finding was consistent with Olsen et al. [38] who reported long-term glycaemic control ($p < 0.0001$) and diabetes duration before and after puberty onset ($p < 0.05$ and $p < 0.001$, respectively) as significantly associated with the development of retinopathy (Table 1). Other findings were generated from samples inclusive of but not specific to the target population.

Prevalence and prediction of nephropathy

Prevalence of diabetic nephropathy was reported in eight papers [32-35,37-40]. Raile et al. [39] reported data from 262 centres and, as previously reported, Salardi et al. [40] from eleven centres and both Olsen et al. [37] and Olsen et al. [38], from 19 paediatric departments (both) and five/six departments of internal medicine; the number of centres from which data were obtained was unclear in James et al. [34]. In all of these five papers renal function indices employed were not in accordance with current best-practice guideline recommendations. These were however utilised by Broe et al. [32] who reported 18 (10.5%) and 17 (14.8%) participants with albuminuria, and Garg et al. [33] who reported data from a single eye/kidney clinic. In a study involving 150 participants, 24 (16%) were reported with albumin excretion indicative of microalbuminuria and eleven (7.3%) with values indicative of macroalbuminuria. Prevalence data were also reported for 121 participants by Kullberg et al. [35]. For this study, neither number of study sites nor detail of study assessment methods for nephropathy were supplied. At recruitment for fundus photography sample ages ranged mean (SD) 12.4 (2.1) - 41.7 (2.4) years, with subgroups A3 aged 21.9 (2.2) years and A4 27.2 (2.3) years. In these subgroups 14% and 13% were reported with urinary albumin excretion greater than 20 mg/L. Factors predicting development of nephropathy were not reported by either Broe et al. [32] or Garg et al. [33].

Prevalence and prediction of hypertension

The prevalence of hypertension was reported in five papers [33-35,40,41]. Schwab et al. [41] and Salardi et al. [40] reported data derived from 195 and eleven centres, respectively, but did not detail young adult cohort numbers. As previously noted, Kullberg et al. [35] reported prevalence data from 121 eligible participants but did not detail numbers of sites.

Criteria for hypertension in adults with diabetes were revised down to 130/80 mmHg earlier this century. All three papers reported the prevalence of hypertension either without stating diagnostic criteria or using what are now out-dated criteria (140/90 mmHg). Kullberg et al. [35] and Salardi et al. [40] reported hypertension by their definitions as occurring in 0% - 9% of participants. Schwab et al. [41] reported raised systolic and diastolic blood pressures in 11% and 2.6% of applicable participants, respectively, with 4.8% receiving pharmacotherapy. Out-dated criteria were also used by Garg et al. [33] who reported blood pressure values categorised by participants' albumin excretion rate grouping. They reported 34% - 72.5% of systolic and 37.7% - 64.9% of diastolic ambulatory blood pressure measurements (mean of 24-hour collections) as above the 90% percentile of normal for age, gender and ethnic group. For participants with macroalbuminuria, over 60% of day and night-time systolic and diastolic measurements were above the 90th percentile of normal values.

Indices employed by James et al. [34] were in accordance with current best-practice guideline recommendations. Blood pressure measurements were documented in 313 and 306 of participants, with 33.9% and 30.7% having mean values within hypertensive ranges, respectively. With anti-hypertensive medication prescribed for 10.2% of participants a total of 201 (48.4%) were classified as hypertensive; at least one documented hypertensive measurement was reported in 35 (48.6%) cohort members prescribed anti-hypertensive medication, across the study period. Participants were more likely to have hypertension if they had no (rather than any) health service contact (OR 0.21, 95% CI 0.1 - 0.51, $p = 0.001$) or a longer diabetes duration (each year, OR 1.05, 95% CI 1.01 - 1.09, $p = 0.006$). This was in addition to use of continuous subcutaneous insulin infusion therapy (OR 1.8, 95% CI 1.2 - 2.7, $p = 0.004$) although this latter finding may have been affected by missing data.

Discussion

This systematic literature review indicated that vascular complications are common amongst young adults with type 1 diabetes although the results reported varied somewhat. Some form of retinopathy occurred in up to almost half of participants; more severe forms affected up to one in ten. One in six was reported with microalbuminuria; one in 14 had macroalbuminuria. Hypertension occurred in almost one in two participants. In outdated high thresholds this decreased to approximately one in ten participants. The frequency of these complications is concerning since they are largely preventable, are occurring alongside an increasing incidence of type 1 diabetes worldwide, and incur high costs in financial and health-related quality of life terms. Ng and Morlet [45] flagged the high prevalence and cost of diabetic retinopathy amongst Australians, but failed to differentiate the particular problems of younger onset and hence greater lifetime burden for those with type 1 diabetes. The DiabCo$t Australia study [46] estimated the minimum annual cost of type 1 diabetes in Australia at between $430 to $570 million in 2008, with expenditure increasing with the presence of complications. Real costs were

acknowledged as higher, as costs associated with disability and premature mortality were not considered.

Identified prevalence rates of retinopathy in this young adult population were elevated compared to recent data for adolescents with type 1 diabetes. Downie et al. [47] reported a prevalence of 12% between 2005–2009, compared to up to 40% and 57.6% in the literature reviewed here [38,40]. The review rate was not dissimilar to rates provided for older cohorts of people with type 1 diabetes (within a decade outside the review age criteria). Karadeniz and Yilmaz [48], Esteves et al. [49] and Roy [50] reported retinopathy prevalence of 33.2%, 44.4% and 63.9%, respectively; discrepancies perhaps reflected the trend of increasing prevalence of complications with increasing diabetes duration and age.

In studies where data were obtained using current best practice recommendations, prediction of development of nephropathy was not reported for the young adult age group. Studies of older cohorts of people with type 1 diabetes found diabetic nephropathy associated with indices of diabetes duration and control (increasing HbA1c), and with prevalence and severity of other forms of vascular disease and population-wide markers of vascular risk such as triglyceride levels and weight [51-55].

The identified prevalence rates of hypertension in this young adult population were also elevated compared to a study involving a slightly older cohort (mean (SD) age 33.8 (11.8) years at baseline), which reported an increase in elevated systolic and diastolic blood pressures over time. In 2003–2004, 17.9% and 6%, respectively, were affected, whereas by 2006–2007 this had increased to 28.8% and 8.2%. The proportion of participants prescribed antihypertensive medication also increased significantly during this period, from 20.7% to 34.2% [56]. However, in another similarly older cohort (mean (SD) age 37 (9) years) only 48% of those diagnosed and treated for hypertension achieved target values [57], indicating little room for complacency. This is consistent with review findings.

The paucity of blood pressure data for young adults and the indication of poor achievement of treatment goals are particular concerns. Hypertension predisposes to stroke, myocardial infarction, cardiac failure and limb amputation as well as other vascular disease manifestations such as retinopathy and nephropathy. A trend seen in slightly older young adults with type 1 diabetes was of any one end-organ manifestation of vascular disease indicating an increased likelihood of concurrent vascular disease in other areas. For example, in cohorts with mild/severe renal failure, 71.4% and 83.3%, respectively, also had hypertension [58]. Early detection and prompt treatment are therefore essential, with general population studies clearly demonstrating early diagnosis and adherence to treatment prevents or delays development and progression of end-organ damage [59].

Adherence to sometimes complex, always life-long medication schedules is challenging. 'Typical' versus 'ideal' medication adherence in patients with hypertension has demonstrated nearly double the relative risk of myocardial infarction, angina and stroke [60]. However, Hill et al. [61] cited achievement of up to 80% adherence rates in routine care and this is especially important for this patient group as cardiovascular disease occurs more than ten times more frequently in those with type 1 diabetes than in age-matched non-diabetes populations [62]. Lack of data on the prevalence of hypertension may hamper prioritisation and appropriate targeting of therapy; important opportunities for treatment may be missed.

Effective prevention interventions rely on identifying modifiable predictors of vascular complications. Data relating specifically to the target population were scarce and this quantitative epidemiological systematic review found glycaemic control as predictive of vascular disease in young adults with type 1 diabetes. Diabetes duration was also flagged, of concern because it is not modifiable and almost half of those who develop the disease do so before age 15 years, many in infancy and childhood [63]. After only nine years with type 1 diabetes almost half of young adults had retinal damage [36] - and probably other vascular disease as well.

On the other hand glycaemic control is modifiable and influential. The deterioration that accrues with disease duration may be ameliorated by better glycaemic control [9,64], with better control being achieved by those who maintain contact and relationships with their diabetes healthcare teams [65]. This flags the crucial importance of ensuring that services are able to support young adults with type 1 diabetes, particularly during the vulnerable period when they leave the paediatric services that supported them as children, establish relationships with adult services and independent self-management practices. It reinforces the importance of regular screening using best practice methods as this offers the best chance for early detection and initiation of appropriate treatment, and consequently to minimise visual loss and blindness, renal failure and dialysis, heart failure and strokes occurring in young adults.

Good quality data are required from adequately powered studies to inform service development, to help nurses and other healthcare professionals risk-stratify and provide appropriate support to young adults with type 1 diabetes, to minimise and defer onset of vascular complications. In most developed countries the data required for high-powered studies are collected routinely by diabetes services. That these data have not been accessed and used to develop algorithms to stratify risk for these young adults is indicative of the lack of priority accorded this problem.

Some limitations apply to the current review. A search for grey literature such as conference abstracts was not undertaken; neither were experts in this field contacted for unpublished data, nor authors for data from age-specific subsets where these data did not appear in publications. Identification of a specific age range to designate 'young adults' was challenging; we opted to focus on those who would have transitioned out of paediatric into adult care, but use of wider age ranges may have yielded additional data.

Caution also needs to be exercised when considering how review findings can be generalised to the target population of young adults with type 1 diabetes as few studies focused solely on representative samples of this specific age group or involved rural populations. Other omissions were the paucity of studies undertaken in developing countries, and limited data indicating participants' ethnicity. Finally, although studies reporting data collected pre 1993 were excluded in light of the definitive Diabetes Control and Complications Trial [9], it may have taken a number of years for these research findings to change practice such that glycaemic control became central in every-day management. Earlier literature reviewed may therefore be poorly representative of current practice and not reflect prevalence of vascular complications in today's young adults. New primary research is required.

Conclusion

This is the first systematic review of the prevalence and predictors of retinopathy, nephropathy and hypertension in young adults with type 1 diabetes. While data were limited, underlying vascular disease manifesting as retinopathy and hypertension was common amongst this group, with development predicted by glycaemic control - and probably diabetes duration. With only one of these two factors amenable to clinical management, findings have implications for clinicians, policy-makers, patients and families: to raise the priority of improving glycaemic control as a means to defer and avoid development of complications which otherwise appear near-inevitable.

Clinical messages of this review are the importance of prevention of loss to follow up and provision of appropriate support, particularly around the vulnerable transition period from paediatric to adult-based care. This would ensure support for optimal glycaemic control and enable regular complication screening to be implemented - essential for early detection and treatment in this age group. Quality data are required to be available to clinicians and patients to stratify risk and guide treatment planning, and to inform service development. The message for policy-makers is that the prevalence rates identified make good preventive care essential. The challenge is to make this a realistic option and available to all young adults with type 1 diabetes.

Additional files

Additional file 1: Search strategy.

Additional file 2: Strengthening the reporting of observational studies in epidemiology (STROBE) checklist.

Additional file 3: Summary of extracted information from included literature.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

Paper drafted, revised and agreed by all authors.

Author information

SJ - RN, CDE, *Doctor of Philosophy (Nursing) student, Faculty of Health, University of Technology, Sydney.* RG - PhD, MN, RN, *Professor of Nursing, Charles Perkins Centre/ Sydney Nursing School, University of Sydney.* JD - PhD, BAg, *Research Assistant, University of Newcastle.* LP - PhD, MSc, RN, *Professor of Nursing Research, and Practice Development, Faculty of Health, University of Technology, Sydney and Prince of Wales Hospital/Sydney and Sydney Eye Hospitals.*

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Author details

[1]Huntsville District Memorial Hospital, Muskoka Algonquin Healthcare, 100 Frank Miller Drive, Huntsville, Ontario P1H 1H7, Canada. [2]Charles Perkins Centre/Sydney Nursing School, University of Sydney, Sydney, New South Wales 2006, Australia. [3]University of Newcastle, University Drive, Callaghan, New South Wales 2308, Australia. [4]Faculty of Health, University of Technology, Sydney, 15 Broadway, Ultimo, New South Wales 2007, Australia.

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Additional file 1: Search strategy.

Type 1 diabetes

1. 'Diabetes Mellitus, Type 1'; or 'Type 1 diabetes'; or 'Insulin Dependent Diabetes Mellitus'; or 'Juvenile Onset Diabetes Mellitus'

Vascular complications

2. 'Diabetic Retinopathy'; or 'Retinopathy'; or 'Eye Diseases'

3. 'Diabetic Nephropathies'; or 'Nephropathy'; or 'Kidney Diseases'

4. 'Hypertension'; or 'High Blood Pressure'

5. 2 OR 3 OR 4

Prevalence

6. 'Prevalence'; or 'Cross-sectional Studies'; or 'Prospective Studies'; or 'Longitudinal Studies'

Summary

7. 1 AND 5 AND 6

Additional file 2: Strengthening the reporting of observational studies in epidemiology (STROBE) checklist

	Arfken et al. 1998	Broe et al. 2014	Garg et al. 1997	James et al. 2014	Kullberg et al. 2002	LeCaire et al. 2006	Olsen et al. 1999	Olsen et al. 2004	Raile et al. 2007	Salardi et al. 2012	Schwab et al. 2006
Title and abstract	√	√	√	√	√	√	√	√	√	√	√
Introduction											
Background/ rationale	√	√	√	√	√	√	√	√	√	√	√
Objectives	√	√	√	√	√	√	√	√	√	√	√
Methods											
Study design	√		√	√	√	√	√	√	√	√	√
Setting	√	√	√	√	√	√	√	√	√	√	√
Participants	√	√	√	√	√	√	√	√	√	√	√
Variables	√	√	√	√	√	√	√	√	√	√	√
Data sources/ measurement	√	√	√	√	√	√	√	√	√	√	√
Bias	√	X	√	X	X	√	X	X	X	√	X
Study size	√	√	X	√	√	√	√	√	√	X	√
Quantitative variables	√	√	√	√	√	√	√	√	√	√	√

Statistical methods	√	√	√	√	√	√	√	√	√	√	√
Results											
Participants	N/A	√	√	√	N/A	√	X	√	N/A	√	N/A
Descriptive data	√	√	√	√	√	√	√	√	√	√	√
Outcome data	√	√	√	√	√	√	√	√	√	√	√
Main results	√	√	√	√	√	√	√	√	√	√	√
Other analysis	√	√	√	√	√	√	√	√	√	√	X
Discussion											
Key results	√	√	√	√	√	√	√	√	√	√	√
Limitations	√	√	X	√	X	√	X	X	X	√	X
Interpretation	√	√	√	√	√	√	√	√	√	√	√
Generalisability	√	√	X	√	√	√	√	√	X	X	√
Other information											
Funding	√	√	√	√	√	√	√	X	√	X	√
Assessment and measurement according to best practice guidelines											
Diabetic retinopathy	√	√	N/A	√	N/A	√	√	√	N/A	√	N/A
Nephropathy	N/A	√	√	X	X	N/A	X	X	X	X	N/A
Hypertension	N/A	N/A	X	√	X	N/A	N/A	N/A	N/A	X	X

(N/A) Not applicable

Additional file 3: Summary of extracted information from included literature.

Aims/purpose/research question; study design; setting; data collection dates; sampling strategy; sample size and characteristics	Method(s) of complication assessment	Relevant findings (excluding data on predictors)
Arfken et al. 1998		
To compare the risk of developing proliferative DR in African-American and White participants with type 1 diabetes Cross-sectional design; case note audit U.S.A.; 'model demonstration units', number unclear Data collection period unclear Sampling strategy unclear; inclusion criteria: subjects with type 1 diabetes (age of onset of ≤ 40 years, continuous insulin usage); African-American or White; at least 2 visits with gradable eye photographs; if > 2 visits, visits chosen to maximise follow-up duration n 312 (n 97 (African-American participants); n 215 (White participants)) *Age: 27.0 (15.0) years (African-American participants); 19.0 (11.0) years (White participants); p = 0.0001 Male: 32% (African-American participants); 45% (White participants); p < 0.03 *Diabetes duration: 9.2 (7.0) years (African-American participants); 8.0 (6.4) years (White participants); p < 0.15	**DR** Photography	**DR** Proliferative: 17.5% (African-American); 10.2% (White participants)

Broe et al. 2014		
To investigate the long-term incidence of proliferative DR, and progression and regression of DR and associated risk factors in young Danish patients with type 1 diabetes Longitudinal cohort study Denmark; number of centres unclear Selection of participants from an earlier study. 16-year follow-up examination data in 2011 compared with participants' baseline 1995 data (the latter shown here). Mean age not reported for 2011 follow-up n 324 (n 185 (participants from baseline 1995 study); n 139 (non-participants from baseline 1995 study)) Baseline (1995) characteristics: *Age: 21.0 (3.3) years (participants from baseline 1995 study); 20.2 (3.2) years (non-participants from baseline 1995 study); $p < 0.03$ *Diabetes duration: 13.5 (3.3) years (participants from baseline 1995 study); 13.0 (2.9) years (non-participants from baseline 1995 study); $p = 0.22$	**DR** Photography **Nephropathy** Two consecutive overnight timed urine samples Microalbuminuria: AER 20 - 200 µg/min Macroalbuminuria: AER >200 µg/min	**DR** *Participants from 1995 study* - Non-proliferative: 61.2% (n 114) Proliferative: 0.5% (n 1) *Non-participants from 1995 study* - Non-proliferative: 51.8% (n 72) Proliferative: 0.7% (n 1) **Nephropathy** *Participants from 1995 study* - Albuminuria (mean AER > 20 µg/min): 10.5% (n 18) *Non-participants from 1995 study* - Albuminuria (mean AER > 20 µg/min): 14.8% (n 17) **HT** *Participants from 1995 study* - Antihypertensive treatment: 5.8% (n 10) *Non-participants from 1995 study* - Antihypertensive treatment: 6.9% (n 9)

Garg et al. 1997		
To determine the relationship between 24-hour ambulatory BP measurements and early renal disease Cross-sectional design U.S.A.; 1 eye/kidney clinic Data collection period unclear Consecutive sampling; inclusion criteria: subjects with type 1 diabetes who had completed the 24-hour ambulatory BP measurements, brought in two timed overnight urine specimens and who attended the clinic were included; exclusion criteria: subjects with a body-mass index greater than 120% of normal for their age and gender n 150 (n 86 (normal AER); n 29 (borderline AER elevation); n 24 (microalbuminuria); n 11 (macroalbuminuria)) *Age: 22.6 (3.3) years (normal AER 22.7 (0.5) years; borderline AER elevation 21.3 (0.6) years; microalbuminuria 23.0 (0.6) years; macroalbuminuria 24.3 (1.0) years) Male: 51.3% (normal AER 52.3%; borderline AER elevation 51.7%; microalbuminuria 45.8%; macroalbuminuria 54.6%) *Diabetes duration: 12.8 (5.0) years (range, 3.5 - 25.8) (normal AER 12.8 (0.6) years; borderline AER elevation 11.1 (0.8) years; microalbuminuria 13.7 (1.0) years; macroalbuminuria 15.0 (1.8) years)	**HT** Ambulatory BP measurements were taken by an oscillometric portable automatic monitor every 30 minutes from 6 a.m. to 10 p.m. and every hour from 10 p.m. to 6 a.m.; readings were downloaded. Office BPs were measured using the appropriate sized cuff and a sphygmomanometer after resting in sitting position for 5 minutes HT > 140/90 mmHg **Nephropathy** Overnight urine collections taken on nights with no evening exercise, alcohol or caffeine intake and when menses, pregnancy, or urinary tract infections were absent Borderline elevation: AER 7.6 - 20 µg/min Microalbuminuria: AER 20.1 - 200 µg/min Macroalbuminuria:	**HT** % 24-hour ambulatory BP measurements indicating - Systolic HT: borderline AER elevation 12.3% (2.8); microalbuminuria 6% (1.8); macroalbuminuia 40.2% (7.6); p < 0.0001 Diastolic HT: borderline AER elevation 11.1% (2.6); microalbuminuria 7.8% (1.5); macroalbuminuria 39.3% (8.8); p < 0.0001 % of ambulatory BP measurements > 90% percentile (mean of 24-hours) - Systolic: borderline AER elevation 48.3% (5.1); microalbuminuria 37.8% (4.9); macroalbuminuria 72.5% (8.4); p < 0.0002 Diastolic: borderline AER elevation 47.3% (4.3); microalbuminuria 40.5% (4.1); macroalbuminuria 64.9% (10.5), p < 0.002

	AER > 200 µg/min	
James et al. 2014		
To identify the prevalence and factors predictive of development of vascular complications in a cohort of young adults with type 1 diabetes Cross-sectional design; case note audit Australia; number unclear Data collected 2010 - 2011 Participants accessing Hunter New England Local Health District public health services, identified through clinic records, hospital attendances and other clinical records n 707 (n 682 (2010); n 707 (2011)) Ophthalmic examinations documented: n 95 (2010); n 85 (2011) ACR measurements documented: n 222 (2010); n 218 (2011) BP measurements documented: n 313 (2010); n 306 (2011) *Age: 23.0 (3.7) years Male: 54.3% *Diabetes duration: 10.2 (5.8) (range 0.2 - 28.3) years Aboriginal and/or Torres Strait Islander 5.6%; Rural participants 42.4%	**DR** Documented **Nephropathy** ≥ one reported ACR measurement above laboratory threshold normal value **HT** ≥ 130/80 mmHg per annum, and/or prescription of anti-hypertensive medication	**DR** *2010* - Any: 13.7% *2011* - Any: 9.4% **Nephropathy** *2010* - ≥ one ACR measurement above laboratory threshold value: 15.1% *2011* - ≥ one ACR measurement above laboratory threshold value: 16.1% ≥ two above threshold value: 12.4% **HT** *2010:* ≥ 130/80 mmHg: 33.9% *2011:* ≥ 130/80 mmHg: 30.7%

		Anti-hypertensive medication: 10.2% Any HT: 48.4%
Kullberg et al. 2002		
To investigate the prevalence and incidence of vascular complications in a population with type 1 diabetes from a well-defined geographical area Cross-sectional design; case note audit Sweden; number of centres unclear 1994 - 1995 Total n 390 (n 258 (age at diabetes onset 0 - 19 years); n 132 (age at diabetes onset 20 - 35 years)) Consecutive sampling from registers from local diabetes centres; inclusion criteria: type 1 diabetes; diagnosed < 36 years of age, during 1983 - 1987, and at the time of onset living within a defined geographical area - consecutive cases Grouped by age at diagnosis: A3 (10 - 14 years) n 75; A4 (15 - 19 years) n 46. *Age at recruitment/fundus photo: A3 21.9 (2.2) years; A4 27.2 (2.3) years Male: A3 56%; A4 61%	**DR** Photography **Nephropathy** Measured with the standard (unstated) method at each clinic **HT** > 140/90 mmHg or on anti-hypertensive medication(s)	**DR** Data not provided specific to target age group *Age at diabetes onset 0 - 19 years* - Microaneurysms: 23.3% > than microaneurysms: 3.9% *Age at diabetes onset 20 - 35 years* - Microaneurysms: 21.2% > than microaneurysms: 11.4% **Nephropathy** UAE > 20 mg/L: A3 14%; A4 13% **HT** Any HT: A3 9%; A4 9%

*Diabetes duration at fundus photo: A3 9.4 (1.8) years; A4 9.8 (1.6) years		
LeCaire et al. 2006		
To examine development of DR in a population-based cohort of persons with incident type 1 diabetes, to investigate the possibility of lowered DR prevalence and severity compared with previous U.S. studies Longitudinal cohort study U.S.A.; number of centres unclear Voluntary recruitment to cohort with inclusion criteria: type 1 diabetes diagnosed from May 1987 - April 1992; ≤ 30 years of age; living within defined area in Southern and Central Wisconsin n 474 (n 420 (4 years diabetes duration (T1)); n 275 (7 years diabetes duration (T2)); n 290 (9 years diabetes duration (T3)); n 68 (14 years diabetes duration (T4))) *Age: T1 14.1 (6.2) years (DR -); 19.5 (7.0) years (DR +) (P ≤ 0.0001). T2 16.1 (6.6) years (DR -); 19.5 (6.4) years (DR +) (P ≤ 0.01). T3 18.8 (7.2) years (DR -); 21.1 (6.4) years (DR +) (P ≤ 0.01). T4 22.2 (8.2) years (DR -); 24.8 (6.3) years (DR +) Male: T1 51% (DR -); 52% (DR +). T2 49% (DR -); 48% (DR +). T3 49% (DR -); 57% (DR +). T4 39% (DR -); 46% (DR +) Ethnicity (White) T1 96% (DR -); 96% (DR +). T2 96% (DR -); 90% (DR +). T3 99% (DR -); 95% (DR +). T4 100% (DR -); 98% (DR +)	**DR** Photography	**DR** Any: T1 6%; T2 23%; T3 47%; T4 73% Minimal non-proliferative: T1 5%; T2 18%; T3 33%; T4 44% Mild non-proliferative: T1 1%; T2 4%; T3 11%; T4 19% Moderate - severe non-proliferative: T1 0.2%; T2 0.4%; T3 2%; T4 10% Proliferative or treated: T1 0%; T2 0.4%; T3 0.3%; T4 0%

Olsen et al. 1999		
To estimate the prevalence of present glycaemic control and the prevalence of microvascular complications in a cohort of children and adolescents who had participated in 2 previous studies Longitudinal cohort study Denmark; 19 paediatric departments and five departments of internal medicine Selection of participants from two previous studies (1987 and 1989) Study n 339 (n 205 > 20 years of age of which n 190 assessed for DR, and n 192 assessed for nephropathy); Median age 21.1 years (range 12.0 - 26.9), male 53.1% and duration 13.2 years (8.9 - 24.5). n and characteristics of sample > 20 years not reported	**DR** Photography **Nephropathy** Two consecutive overnight timed urine samples. If AER was > 20 µg/min in one of the two samples a third sample was collected. The mean of 2 consistent AER samples was used in the analaysis Microalbuminuria: AER of 20 - 150 µg/min Macroalbuminuria: AER >150 µg/min	*Age > 20 years:* **DR** Minimal non-proliferative: 48.9% Moderate non-proliferative plus: 20% **Nephropathy** Microalbuminuria: 9.4% Macroalbuminuria: 4.7%
Olsen et al. 2004		
To determine the effect of the pre-pubertal duration of diabetes on early DR and elevated AER Longitudinal cohort study	**DR** Photography	**DR** Any: 57.6%

Denmark; 19 paediatric departments and six departments of internal medicine Selection of participants from an earlier study. Eight year follow-up data (1995 - 1996) n 353 (n 304 (Onset of diabetes < 12 years (pre-pubertal); n 49 (Onset of diabetes ≥ 12 years (pubertal/postpubertal)))); n 339 had urine samples taken *Age: 20.4 (3.2) years (Onset of diabetes < 12 (pre-pubertal)); 24.2 (1.3) years (Onset of diabetes ≥ 12 years (pubertal/post-pubertal)); p < 0.0001 Male: 51.3% (Onset of diabetes < 12 years (pre-pubertal)); 65.3% (Onset of diabetes ≥ 12 years (pubertal/post-pubertal)) *Duration: 13.8 (3.2) years (Onset of diabetes <12 years (pre-pubertal)); 10.7 (1.3) years (Onset of diabetes ≥ 12 years (pubertal/post-pubertal)); p < 0.0001)	**Nephropathy** Two out of three consecutive overnight timed urine samples Microalbuminuria: AER 20 - 150 µg/min Macroalbuminuria: AER >150 µg/min	**Nephropathy** AER > 20 µg/min: 12.7%
Raile et al. 2007		
To analyse the prevalence of nephropathy in a nationwide prospective survey Prospective cross-sectional design, documentation survey Germany and Austria; 262 centres Data collection period unclear but ceased February 2007	**Nephropathy** Measurement of ACR in a random spot collection, 24-hour collection with creatinine, or timed (e.g. overnight) collection. Microalbuminuria or macroalbuminuria was defined as at least two increased urine albumin	**Nephropathy** Microalbuminuria: 3.3% Macroalbuminuria: 0.2% End stage renal disease: 0.8%

Sample from German Diabetes Documentation System with inclusion criteria of at least 2 documented urine analyses; strategy unclear n 27,805 (n 26,644 (normal). n 919 (microalbuminuria); n 52/229 (macroalbuminuria/end stage renal disease) *Age at last visit: 21.1 (0.1) years (normal); 28.7 (0.6) years (microalbuminuria); 37.2 (1.2) years (macroalbuminuria/ end stage renal disease); p < 0.0001 Male: 52.6% (normal); 52.1% (microalbuminuria); 58% (macroalbuminuria/end stage renal disease) *Diabetes duration: 8.3 (0.05) years (normal); 12.6 (0.4) years (microalbuminuria); 20.1 (0.9) years (macroalbuminuria/ end stage renal disease); p < 0.0001	tests during the follow-up Microalbuminuria: AER 20 - 199 µg/min or an urinary albumin creatinine ≥ 2.5 mg/mmol Macroalbuminuria: AER ≥ 200 µg/min or an urinary albumin creatinine ≥ 35 mg/mmol	
Salardi et al. 2012		
To compare the effects of the pre-pubertal duration of diabetes on the occurrence of complications in two groups of patients after the same number with years of the disease Cross-sectional design Italy; 11 centres 2007 - 2009 Patients initially diagnosed and treated between 1981 - 1992, those who were aged 0 - 3 years and those who were in puberty or post-pubertal at the onset of type 1 diabetes; obtained from individual centres but	**DR** Photography	**DR** *Entire cohort* - Any after 20 years diabetes duration: 55% Mild after 20 years diabetes duration: 40% Moderate non-proliferative after 20 years diabetes duration: 9% Severe non-proliferative after 20 years diabetes duration: 4% Proliferative after 20 years diabetes duration: 2%

sampling strategy unclear n 105 (n 53 (very young pre-pubertal onset); n 52 (pubertal onset)); n 86 assessed for UAE; n 89 assessed for HT *Age: 22.0 (4.5) years (very young pre-pubertal onset); 31.6 (4.1) years (pubertal onset) Male: 43% (41.5% (very young pre-pubertal onset); 44.2% (pubertal onset)) *Diabetes duration: 19.7 (4.0) (range 15 - 28.5) years; n 69 (< 20 years); n 36 (≥ 20 years)		*Very young pre-pubertal-onset group* - Any: 40% Mild: 30% Moderate to severe: 10% Any < 20 years diabetes duration: 27% Any > 20 years diabetes duration: 88% *Pubertal onset group* - Any: 71% Mild: 52% Moderate to severe: 20% Any < 20 years diabetes duration: 63% Any > 20 years diabetes duration: 63%
	Nephropathy UAE or AER - Microalbuminuria: UAE 30 - 300 mg/day or AER ≥ 20 µg/min Macroalbuminuria: UAE > 300 mg day or AER > 150 µg/min	**Nephropathy** *Entire cohort* - Abnormal UAE: 7% *Very young pre-pubertal-onset group* - Abnormal UAE: 4% *Pubertal onset group* - Abnormal UAE: 9%
	HT BP was measured using a standard sphygmanometer with patients seated, and calculated as the mean of two measurements	**HT** *Entire cohort* - Any: 3% *Very young pre-pubertal-onset group* - Any: 0%

	HT: > 140/90 mmHg	*Pubertal onset group* - Any: 7%
Schwab et al. 2006		
To ascertain the type and prevalence rate, age and sex distribution of cardiovascular risk factors in type 1 diabetic patients up to 26 years of age Cross-sectional design, documentation survey Germany and Austria; 195 centres 2003 - 2004 Sampled consecutive cases from a joint-national register; inclusion criteria: type 1 diabetes. n 27,358 (n 25,184 assessed for raised systolic BP; n 25,178 assessed for raised diastolic BP; n 27,358 assessed for HT treatment) Cohort divided into pre-pubertal (0.25 - 11 years), pubertal (12 - 16 years) and young adulthood (17 - 26 years) based upon developmental stage Size of each cohort unclear *Age: 7.5 (2.5) years (pre-pubertal); 13.7 (1.4) years (pubertal); 18.5 (2.3) years (young adulthood) (P < 0.0001) Male: 51.7% (pre-pubertal); 51.7% (pubertal); 52.5% (young adulthood) (P value NS)	**HT** Use of a sphygmanometer. Median value calculated from at least three measurements HT: Average systolic or diastolic BP ≥ to the 95th percentile for age and sex. Values not provided for adults	**HT** Systolic: 8.1% Diastolic: 2.5% Raised systolic BP: 5.8% (pre-pubertal); 7.4% (pubertal); 11% (young adulthood); p < 0.0001 Raised diastolic BP: 3.9% (pre-pubertal); 3.2% (pubertal); 2.6% (young adulthood); p < 0.0001 Receiving anti-hypertensive medication: 2.1% (0.2% (pre-pubertal); 1.4% (pubertal); 4.8% (young adulthood)); p < 0.0001

*Diabetes duration: 2.5 (2.3) years (pre-pubertal); 4.9 (3.6) years (pubertal); 8.2 (4.8) years (young adulthood) ($P < 0.0001$)		

(ACR) Albumin-creatinine ratio (AER) Albumin excretion rate (BP) Blood pressure (DR) Diabetic retinopathy
(HT) Hypertension (n) Number (OR) Odds ratio (P) Probability (UAE) Urinary albumin excretion *Mean (SD)

Appendix 2: Search strategy

Type 1 diabetes

1. 'Diabetes Mellitus, Type 1', or 'Type 1 diabetes', or 'Insulin Dependent Diabetes Mellitus' or 'Juvenile Onset Diabetes Mellitus'

Vascular complications

2. 'Diabetic Retinopathy', or 'Retinopathy' or 'Eye Diseases'

3. 'Diabetic Nephropathies', or 'Nephropathy' or 'Kidney Diseases'

4. 'Hypertension' or 'High Blood Pressure'

5. 2 OR 3 OR 4

Prevalence

6. 'Prevalence', or 'Cross-sectional Studies', or 'Prospective Studies' or 'Longitudinal Studies'

Summary

7. 1 AND 5 AND 6

Appendix 3: Strengthening the reporting of observational studies in epidemiology (STROBE) checklist

	Arfken et al. 1998	Broe et al. 2014	Broe et al. 2014	Carlsen et al. 2016	Casey et al. 2014	Garg et al. 1997	James et al. 2014	Kullberg et al. 2002	LeCaire et al. 2006	Marshall et al. 2015	Olsen et al. 1999	Olsen et al. 2004	Pinhas-Hamiel et al. 2014	Raile et al. 2007	Rasmussen et al. 2014	Salardi et al. 2012	Schwab et al. 2006	Steinbeck et al. 2015
Title and abstract	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Introduction																		
Background/rationale	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Objectives	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Methods																		
Study design	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Setting	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Participants	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Variables	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Data sources/ measurement	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√

Bias	√	X	X	X	√	√	X	X	√	√	X	X	√	X	X	√	X	X
Study size	√	√	√	√	√	X	√	√	√	√	√	√	√	√	√	X	√	√
Quantitative variables	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Statistical methods	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Results																		
Participants	N/A	√	√	√	N/A	√	N/A	√	√	√	X	√	√	N/A	√	√	N/A	√
Descriptive data	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Outcome data	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Main results	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Other analysis	√	√	√	√	√	√	√	√	√	√	√	√	X	√	X	√	X	X
Discussion																		
Key results	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Limitations	√	√	√	√	X	X	√	X	√	√	X	X	√	X	√	√	X	√
Interpretation	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Generalisability	√	√	√	√	√	X	√	√	X	X	√	√	√	X	X	X	√	√
Other information																		
Funding	√	√	√	X	X	√	√	√	√	X	√	X	X	√	√	X	√	√

Assessment and measurement according to best practice guidelines																		
Diabetic retinopathy	√	√	√	√	√	N/A	√	N/A	√	N/A	√	√	N/A	N/A	√	√	N/A	X
Nephropathy	N/A	√	√	√	X	√	X	X	N/A	√	X	X	N/A	X	N/A	X	N/A	X
Hypertension	N/A	N/A	N/A	N/A	X	X	√	X	N/A	√	N/A	N/A	X	N/A	N/A	X	X	N/A

N/A = Not applicable.

Appendix 4: Summary of extracted information from included literature

Aims/purpose/research question; study design; setting; data collection dates; sampling strategy; sample size and characteristics	Method(s) of complication assessment	Relevant findings (excluding data on predictors)
Arfken et al. 1998		
To compare the risk of developing proliferative DR in African-American and white participants with type 1 diabetes Cross-sectional design; case note audit U.S.A.; 'model demonstration units', number unclear Data collection period unclear Sampling strategy unclear; inclusion criteria: subjects with type 1 diabetes (age of onset of ≤ 40 years, continuous insulin usage); African-American or white; at least 2 visits with gradable eye photographs; if > 2 visits, visits chosen to maximise follow-up duration n = 312 (n = 97 (African-American participants); n = 215 (white participants))	**DR** Photography	**DR** Proliferative: 17.5% (African-American); 10.2% (white participants)

*Age: 27.0 (15.0) years (African-American participants); 19.0 (11.0) years (white participants); p = 0.0001 Male: 32% (African-American participants); 45% (white participants); p < 0.03 *Diabetes duration: 9.2 (7.0) years (African-American participants); 8.0 (6.4) years (white participants); p < 0.15		
Broe et al. 2014		
To investigate the long-term incidence of proliferative DR, and progression and regression of DR and associated risk factors in young Danish patients with type 1 diabetes Longitudinal cohort study Denmark; number of centres unclear Selection of participants from an earlier study. 16-year follow-up examination data in 2011 compared with participants' baseline 1995 data (the latter shown here). Mean age not reported for 2011 follow-up n = 324 (n = 185 (participants from baseline 1995 study); n = 139 (non-participants from baseline 1995 study))	**DR** Photography **Nephropathy** Two consecutive overnight timed urine samples Micro-albuminuria:	**DR** *Participants from 1995 study* - Non-proliferative: 61.2% (n = 114) Proliferative: 0.5% (n = 1) *Non-participants from 1995 study* - Non-proliferative: 51.8% (n = 72) Proliferative: 0.7% (n = 1) **Nephropathy** *Participants from 1995 study* - Albuminuria (mean AER > 20 µg/min): 10.5% (n = 18)

Baseline (1995) characteristics: *Age: 21.0 (3.3) years (participants from baseline 1995 study); 20.2 (3.2) years (non-participants from baseline 1995 study); p < 0.03 *Diabetes duration: 13.5 (3.3) years (participants from baseline 1995 study); 13.0 (2.9) years (non-participants from baseline 1995 study); p = 0.22	AER 20 - 200 µg/min Macro-albuminuria: AER > 200 µg/min	*Non-participants from 1995 study* - Albuminuria (mean AER > 20 µg/min): 14.8% (n = 17) **HT** *Participants from 1995 study* - Anti-hypertensive treatment: 5.8% (n = 10) *Non-participants from 1995 study* - Anti-hypertensive treatment: 6.9% (n = 9)
Broe et al. 2014		
To examine retinal vessel calibers as 16-year predictors of diabetic nephropathy, neuropathy and proliferative retinopathy in a young population-based Danish cohort with type 1 diabetes Longitudinal cohort study Denmark; number unclear Data collected unclear Participants identified from a nationwide population-based	**DR** Photography	**DR** *Participants* - Non-proliferative: 54.6% Proliferative: 0.5% *Non-participants* - Non-Proliferative: 44.4% Proliferative: 0%

paediatric cohort of Danish children with type 1 diabetes Comparison made between participants in the follow-up study and patients who were available for follow-up but declined to participate n = 248 (n = 185 (participants); n = 63 (non-participants)) *Age: 21 (3.3) years (participants); 20.3 (3.2) years (non-participants); p = 0.13 Male: 49.7% of participants; 57.1% of non-participants; p = 0.31 *Diabetes duration: 13.5 (3.3) years (participants); 13.1 (2.8) years (non-participants); p = 0.52	**Nephropathy** Mean of at least 2 timed overnight urine collections Micro-albuminuria: AER of 20 - 200 µg/min Macro-albuminuria: AER > 200 µg/min	**Nephropathy** *Participants* - Micro-albuminuria: 7.6% Macro-albuminuria: 9.2% *Non-participants* - Micro-albuminuria: 7.0% Macro-albuminuria: 7.0%
Carlsen et al. 2016		
To assess longitudinal glycaemic control and the prevalence of retinopathy and nephropathy in young people with type 1 diabetes in Norway Longitudinal cohort study Norway; 21 paediatric centres, and 31 of 49 clinics from 3 of the 4 Norwegian health regions Data collected 2013	**DR** Photographs and/or fundoscopy	**DR** Non-proliferative: 13% Diabetes duration < 10 years: 2.8% Diabetes duration 10 - 20 years: 13.6% Diabetes duration > 20 years: 27.3%

Data obtained by linking 2 nationwide population-based medical quality registries: the Norwegian Diabetes Register for Adults and the Norwegian Childhood Diabetes Registry n = 874 (both retinal and ACR screening) (n = 176 (diabetes duration < 10 years); n = 568 (diabetes duration 10 - 20 years); n = 128 (diabetes duration > 20 years)) Age: Median (with 10 - 90 percentiles) 23.0 (19.0 - 29.0) years Male: 51% Diabetes duration: Median (with 10 - 90 percentiles) 15.0 (8.3 - 22.0) years	**Nephropathy** Micro-albuminuria: ACR 3 - 30 mg/mmol in at least 2 out of 3 consecutive urine samples Macro-albuminuria: ACR > 30 mg/mmol in at least 2 out of 3 consecutive urine samples	Proliferative: 3% Diabetes duration < 10 years: 0% Diabetes duration 10 - 20 years: 3.7% Diabetes duration > 20 years: 10.2% **Nephropathy** Micro-albuminuria: 10% Diabetes duration < 10 years: 9.7% Diabetes duration 10 - 20 years: 9.3% Diabetes duration > 20 years: 11.7% Macro-albuminuria: 3% Diabetes duration < 10 years: 0.6% Diabetes duration 10 - 20 years: 3.2% Diabetes duration > 20 years: 3.1% 40% of those with macro-albuminuria were treated with anti-hypertensive medication

Casey et al. 2014		
To determine attendance rates at a dedicated young adult diabetes clinic and whether poor attendance is a predictor of adverse outcomes Cross-sectional retrospective documentation survey Rep. of Ireland; 1 diabetes centre Data from October 2009 - December 2011 Consecutive sampling n = 137 *Age: 22.9 (2.0) years Male: 52% Diabetes duration: 9.5 years	**DR** Photography **Nephropathy** Unclear how measured **HT** Unclear how measured	**DR** Any: 19% **Nephropathy** Micro-albuminuria: 5.8% Proteinuria: 0.7% **HT** Overall: 2.9%
Garg et al. 1997		
To determine the relationship between 24-hour ambulatory blood pressure measurements and early renal disease Cross-sectional design U.S.A.; 1 eye/kidney clinic Data collection period unclear Consecutive sampling; inclusion criteria: subjects with type	**HT** Ambulatory blood pressure measurements were taken by an oscillometric portable automatic monitor every 30 minutes from 6 a.m. to 10 p.m. and every hour	**HT** *% 24-hour ambulatory blood pressure measurements indicating* - Systolic HT: Borderline AER elevation 12.3% (2.8); micro-albuminuria 6% (1.8);

1 diabetes who had completed the 24-hour ambulatory blood pressure measurements, brought in two timed overnight urine specimens and who attended the clinic were included; exclusion criteria: subjects with a body-mass index greater than 120% of normal for their age and gender n = 150 (n = 86 (normal AER); n = 29 (borderline AER elevation); n = 24 (micro-albuminuria); n = 11 (macro-albuminuria)) *Age: 22.6 (3.3) years (22.7 (0.5) years (normal AER); 21.3 (0.6) years (borderline AER elevation); 23.0 (0.6) years (micro-albuminuria); 24.3 (1.0) years (macro-albuminuria)) Male: 51.3% (52.3% (normal AER); 51.7% (borderline AER elevation); 45.8% (micro-albuminuria); 54.6% (macro-albuminuria)) *Diabetes duration: 12.8 (5.0) years (range 3.5 - 25.8) (12.8 (0.6) years (normal AER); 11.1 (0.8) years (borderline AER elevation); 13.7 (1.0) years (micro-	from 10 p.m. to 6 a.m.; readings were downloaded. Office blood pressures were measured using the appropriate sized cuff and a sphygmomanometer after resting in sitting position for 5 minutes HT > 140/90 mmHg **Nephropathy** Overnight urine collections taken on nights with no evening exercise, alcohol or caffeine intake and when menses, pregnancy or urinary tract infections were absent Borderline elevation: AER 7.6 - 20 µg/min Micro-albuminuria: AER 20.1 - 200 µg/min Macro-albuminuria:	macro-albuminuria 40.2% (7.6); p < 0.0001 Diastolic HT: Borderline AER elevation 11.1% (2.6); micro-albuminuria 7.8% (1.5); macro-albuminuria 39.3% (8.8); p < 0.0001 *% of ambulatory blood pressure measurements > 90% percentile (mean of 24-hours)* - Systolic: Borderline AER elevation 48.3% (5.1); micro-albuminuria 37.8% (4.9); macro-albuminuria 72.5% (8.4); p < 0.0002 Diastolic: Borderline AER elevation 47.3% (4.3); micro-albuminuria 40.5% (4.1); macro-albuminuria 64.9% (10.5);

albuminuria); 15.0 (1.8) years (macro-albuminuria))	AER > 200 µg/min	p < 0.002
James et al. 2014		
To identify the prevalence and factors predictive of development of vascular complications in a cohort of young adults with type 1 diabetes Cross-sectional design; case note audit Australia; number unclear Data collected 2010 - 2011 Participants accessing Hunter New England Local Health District public health services, identified through clinic records, hospital attendances and other clinical records n = 707 (n = 682 (2010); n = 707 (2011)) Ophthalmic examinations documented: n = 95 (2010); n = 85 (2011) ACR measurements documented: n = 222 (2010); n = 218 (2011) BP measurements documented: n = 313 (2010); n = 306 (2011)	**DR** Documented **Nephropathy** ≥ one reported ACR measurement above laboratory threshold normal value **HT** ≥ 130/80 mmHg per annum, and/or prescription of anti-hypertensive	**DR** *2010* - Any: 13.7% *2011* - Any: 9.4% **Nephropathy** *2010* - ≥ one ACR measurement above laboratory threshold value: 15.1% *2011* - ≥ one ACR measurement above laboratory threshold value: 16.1% ≥ two above threshold value: 12.4% **HT** *2010:* ≥ 130/80 mmHg: 33.9%

*Age: 23.0 (3.7) years Male: 54.3% *Diabetes duration: 10.2 (5.8) (range 0.2 - 28.3) years Aboriginal and/or Torres Strait Islander 5.6%; Rural participants 42.4%	medication	*2011:* ≥ 130/80 mmHg: 30.7% Anti-hypertensive medication: 10.2% Any HT: 48.4%
Kullberg et al. 2002		
To investigate the prevalence and incidence of vascular complications in a population with type 1 diabetes from a well-defined geographical area Cross-sectional design; case note audit Sweden; number of centres unclear 1994 - 1995 n = 390 (n = 258 (age at diabetes onset 0 - 19 years); n = 132 (age at diabetes onset 20 - 35 years)) Consecutive sampling from registers from local diabetes centres. Inclusion criteria: type 1 diabetes; diagnosed < 36 years of age; during 1983 - 1987; and at the time of onset living within a defined geographical area - consecutive cases	**DR** Photography **Nephropathy** Measured with the standard (unstated) method at each clinic	**DR** Data not provided specific to target age group *Age at diabetes onset 0 - 19 years -* Micro-aneurysms: 23.3% > than micro-aneurysms: 3.9% *Age at diabetes onset 20 - 35 years -* Micro-aneurysms: 21.2% > than micro-aneurysms: 11.4% **Nephropathy** UAE > 20 mg/L: A3 14%; A4 13%

Grouped by age at diagnosis: A3 (10 - 14 years) n = 75; A4 (15 - 19 years) n = 46 *Age at recruitment/fundus photo: A3 21.9 (2.2) years; A4 27.2 (2.3) years Male: A3 56%; A4 61% *Diabetes duration at fundus photo: A3 9.4 (1.8) years; A4 9.8 (1.6) years	**HT** > 140/90 mmHg or on anti-hypertensive medication(s)	**HT** Any HT: A3 9%; A4 9%
LeCaire et al. 2006		
To examine development of DR in a population-based cohort of persons with incident type 1 diabetes, to investigate the possibility of lowered DR prevalence and severity compared with previous U.S. studies Longitudinal cohort study U.S.A.; number of centres unclear Voluntary recruitment to cohort with inclusion criteria: type 1 diabetes diagnosed from May 1987 - April 1992; ≤ 30 years of age; living within a defined area in Southern and Central Wisconsin n = 474 (n = 420 (4 years diabetes duration (T1)); n = 275	**DR** Photography	**DR** Any: T1 6%; T2 23%; T3 47%; T4 73% Minimal non-proliferative: T1 5%; T2 18%; T3 33%; T4 44% Mild non-proliferative: T1 1%; T2 4%; T3 11%; T4 19% Moderate - severe non-proliferative: T1 0.2%; T2 0.4%; T3 2%; T4 10% Proliferative or treated: T1 0%; T2 0.4%; T3 0.3%; T4 0%

(7 years diabetes duration (T2)); n = 290 (9 years diabetes duration (T3)); n = 68 (14 years diabetes duration (T4))) *Age: T1 14.1 (6.2) years (DR -); 19.5 (7.0) years (DR +) ($p \leq 0.0001$). T2 16.1 (6.6) years (DR -); 19.5 (6.4) years (DR +) ($p \leq 0.01$). T3 18.8 (7.2) years (DR -); 21.1 (6.4) years (DR +) ($p \leq 0.01$). T4 22.2 (8.2) years (DR -); 24.8 (6.3) years (DR +) Male: T1 51% (DR -); 52% (DR +). T2 49% (DR -); 48% (DR +). T3 49% (DR -); 57% (DR +). T4 39% (DR -); 46% (DR +) Ethnicity (white) T1 96% (DR -); 96% (DR +). T2 96% (DR -); 90% (DR +). T3 99% (DR -); 95% (DR +). T4 100% (DR -); 98% (DR +)		
Marshall et al. 2015		
To assess change in glycaemic control concurrent with increased clinic visits, HbA1c testing and education. Rates of complications were also examined Longitudinal cohort study Rwanda; number of centres unclear	**Nephropathy** Micro-albuminuria: ACR of 30 - 399 mg/g in a spot urine sample Macro-albuminuria:	**Nephropathy** *Overall* Micro-albuminuria: 21% Macro-albuminuria: 4.7% *HbA1c measurement 1 year after*

Data collected June 2009 - November 2010
Participants were registered members of the Rwanda Life for a Child Program who had their first HbA1c measured between June 2009 - November 2010. Participants were residents of Rwanda aged ≤ 25 years needing assistance with obtaining insulin and diabetes supplies
n = 286 (n = 214 (HbA1c measurement 1 year after baseline);
n = 72 (no HbA1c measurement 1 year after baseline);
n = 70 (no HbA1c measurement 2 years after baseline);
n = 125 (HbA1c measurement at both 1 and 2 years following baseline))
Nephropathy measurements tested:
n = 182 (n = 112 (HbA1c measurement 1 year after baseline);
n = 37 (no HbA1c measurement 1 year after baseline);
n = 33 (no HbA1c measurement 2 years after baseline))
	ACR ≥ 300 mg/g
	
	HT
	A manual cuff for a portion of 2009 and then by an automatic BP
		baseline -
		Overall
		Micro-albuminuria: 18.8%
		Yes
		Micro-albuminuria: 20.5%
		Macro-albuminuria: 6.2%
		No
		Micro-albuminuria: 21.6%
		Macro-albuminuria: 0%
		HbA1c measurement 2 years after baseline -
		No
		Micro-albuminuria: 21.2%
		Macro-albuminuria: 3%
		HT
		Overall: 31.8%

*Age: 18.6 (4.5) years (18.3 (4.4) years (HbA1c measurement 1 year after baseline); 19.4 (4.7) years (no HbA1c measurement 1 year after baseline); 19.9 (4.3) years (no HbA1c measurement 2 years after baseline)) Male: 46.5% (44.9% (HbA1c measurement 1 year after baseline); 51.4% (no HbA1c measurement 1 year after baseline); 67.1% (no HbA1c measurement 2 years after baseline)) *Diabetes duration: 3.4 (3.1) years (3.3 (2.9) years (HbA1c measurement 1 year after baseline); 3.5 (3.8) years (no HbA1c measurement 1 year after baseline); 4.0 (3.4) years (no HbA1c measurement 2 years after baseline))	machine and cuff for the duration of follow-up Under 18 years of age: above 95th percentile considered hypertensive 18 years of age and over: ≥ 130/80 mmHg or a history of BP medication Rates calculated by adding the results of those under 18 years of age with those 18 years of age and over	*HbA1c measurement 1 year after baseline* - Overall: 44.9% Yes: 30.8% No: 34.7% *HbA1c measurement 2 years after baseline* - *No:* 38.6%
Olsen et al. 1999		
To estimate the prevalence of present glycaemic control and the prevalence of micro-vascular complications in a cohort of children and adolescents who had participated in two previous studies Longitudinal cohort study Denmark; 19 paediatric departments and five departments	 **DR** Photography **Nephropathy** Two consecutive overnight timed	*Age > 20 years:* **DR** Minimal non-proliferative: 48.9% Moderate non-proliferative plus: 20% **Nephropathy** Micro-albuminuria: 9.4%

of internal medicine Selection of participants from two previous studies (1987 and 1989) n = 339 (n = 205 (> 20 years of age of which n = 190 assessed for DR, and n = 192 assessed for nephropathy)) Median age: 21.1 (range 12.0 - 26.9) years Male: 53.1% Diabetes duration: 13.2 (range 8.9 - 24.5) years n and characteristics of sample > 20 years not reported	urine samples. If AER was > 20 µg/min in one of the two samples a third sample was collected. The mean of 2 consistent AER samples was used in the analysis Micro-albuminuria: AER of 20 - 150 µg/min Macro-albuminuria: AER >150 µg/min	Macro-albuminuria: 4.7%
Olsen et al. 2004		
To determine the effect of the pre-pubertal duration of diabetes on early DR and elevated AER Longitudinal cohort study Denmark; 19 paediatric departments and 6 departments of internal medicine Selection of participants from an earlier study. 8-year follow-up data (1995 - 1996) n = 353 (n = 304 (onset of diabetes < 12 years (pre-	**DR** Photography **Nephropathy** Two out of three consecutive overnight timed urine samples Micro-albuminuria: AER 20 - 150 µg/min Macro-albuminuria:	**DR** Any: 57.6% **Nephropathy** AER > 20 µg/min: 12.7%

pubertal); n = 49 (onset of diabetes ≥ 12 years (pubertal/post-pubertal)))); n = 339 had urine samples taken *Age: 20.4 (3.2) years (onset of diabetes < 12 (pre-pubertal)); 24.2 (1.3) years (onset of diabetes ≥ 12 years (pubertal/post-pubertal)); p < 0.0001 Male: 51.3% (onset of diabetes < 12 years (pre-pubertal)); 65.3% (onset of diabetes ≥ 12 years (pubertal/post-pubertal)) *Diabetes duration: 13.8 (3.2) years (onset of diabetes < 12 years (pre-pubertal)); 10.7 (1.3) years (onset of diabetes ≥ 12 years (pubertal/post-pubertal)); p < 0.0001	AER >150 μg/min	
Pinhas-Hamiel et al. 2014		
To determine the prevalence of overweight and obesity among children, adolescents and young adults with type 1 diabetes, and to assess the prevalence of the metabolic syndrome and its components Cross-sectional design Israel; 1 centre	**HT** Systolic and/or diastolic blood pressure above the 95th percentile for age and sex	**HT** Overall: 20.8% Normal weight: 16.6%; Overweight: 25.8%; Obese: 64.7%; p < 0.001

Data collected 2012 - 2013 Patients accessing the Juvenile Diabetes Clinic, Maccabi Health centre, Raanana n = 326 (n = 247 (normal weight); n = 62 (overweight); n = 17 Obesity) *Age: 18.5 (6) years (18.1 (6.1) years (normal weight); 19.7 (5.2) years (overweight); 19.1 (6.3) years (obese)); p = 0.17 Male: 48.5% (49.8% (normal weight); 38.7% (overweight); 64.7% (obese)); p = 0.11 Diabetes duration: Median IQR 75 (4.9 - 11.6) years (6.9 (4.6 - 11.5) years (normal weight); 7.8 (6.4 - 12.4) years (overweight); 9.4 (6.3 - 11.6) years (obese)); p = 0.12		Patients treated with angiotensin-converting enzyme inhibitors or angiotensin receptor blockers - Overall: 3.7% Normal weight: 3.3% Overweight: 3.2% Obese: 11.8%
Raile et al. 2007		
To analyse the prevalence of nephropathy in a nationwide prospective survey Prospective cross-sectional design, documentation survey	**Nephropathy** Measurement of ACR in a random spot collection, 24-hour collection	**Nephropathy** Micro-albuminuria: 3.3% Macro-albuminuria: 0.2%

Germany and Austria; 262 centres Data collection period unclear but ceased February 2007 Sample from German Diabetes Documentation System with inclusion criteria of at least 2 documented urine analyses; strategy unclear n = 27,805 (n = 26,644 (normal); n = 919 (micro-albuminuria); n = 52/229 (macro-albuminuria/end stage renal disease)) *Age at last visit: 21.1 (0.1) years (normal); 28.7 (0.6) years (micro-albuminuria); 37.2 (1.2) years (macro-albuminuria/end stage renal disease); p < 0.0001 Male: 52.6% (normal); 52.1% (micro-albuminuria); 58% (macro-albuminuria/end stage renal disease) *Diabetes duration: 8.3 (0.05) years (normal); 12.6 (0.4) years (micro-albuminuria); 20.1 (0.9) years (macro-albuminuria/end stage renal disease); p < 0.0001	with creatinine, or timed (e.g. overnight) collection Micro-albuminuria or macro-albuminuria was defined as at least two increased urine albumin tests during the follow-up Micro-albuminuria: AER 20 - 199 µg/min or a urinary albumin creatinine ≥ 2.5 mg/mmol Macro-albuminuria: AER ≥ 200 µg/min or a urinary albumin creatinine ≥ 35 mg/mmol	End stage renal disease: 0.8%

Rasmussen et al. 2014		
To investigate micro-aneurysm count as a predictor of long-term progression of DR in young patients with type 1 diabetes Longitudinal cohort study Denmark; number of centres unclear Data collected 1995 Data only provided here in relation to baseline Participants are part of the Danish Cohort of Pediatric Diabetes 1987 n = 138 (n = 80 (DR); n = 58 (no DR)) *Age: n = 132, 20.6 (3.4) years (21.1 (3.1) years (DR); 20 (3.7) years (no DR)); p = 0.11 Male: 54.4% (55% (DR); 53.5 (no DR)); p = 0.86 *Diabetes duration: n = 133, 12.9 (3.1) years (13.4 (3.2) years (DR); 12.3 (2.9) years (no DR)); p < 0.02	**DR** Photography	**DR** Mild non-proliferative: 58%

Salardi et al. 2012		
To compare the effects of the pre-pubertal duration of diabetes on the occurrence of complications in two groups of patients after the same number of years with the disease Cross-sectional design Italy; 11 centres 2007 - 2009 Patients initially diagnosed and treated between 1981 - 1992, those who were aged 0 - 3 years and those who were in puberty or post-pubertal at the onset of type 1 diabetes; obtained from individual centres but sampling strategy unclear n = 105 (n = 53 (very young pre-pubertal onset); n = 52 (pubertal onset)); n = 69 (< 20 years); n = 36 (≥ 20 years) n = 86 assessed for UAE; n = 89 assessed for HT *Age: 22.0 (4.5) years (very young pre-pubertal onset); 31.6 (4.1) years (pubertal onset) Male: 43% (41.5% (very young pre-pubertal onset); 44.2%	**DR** Photography	**DR** *Entire cohort* - Any after 20 years diabetes duration: 55% Mild after 20 years diabetes duration: 40% Moderate non-proliferative after 20 years diabetes duration: 9% Severe non-proliferative after 20 years diabetes duration: 4% Proliferative after 20 years diabetes duration: 2% *Very young pre-pubertal-onset group* - Any: 40% Mild: 30% Moderate to severe: 10% Any < 20 years diabetes duration: 27%

(pubertal onset)) *Diabetes duration: 19.7 (4.0) (range 15 - 28.5) years	 **Nephropathy** UAE or AER - Micro-albuminuria: UAE 30 - 300 mg/day or AER ≥ 20 µg/min Macro-albuminuria: UAE > 300 mg day or AER > 150 µg/min **HT** BP was measured using a standard sphygmanometer with patients seated, and calculated as the mean of two measurements HT: > 140/90 mmHg	Any > 20 years diabetes duration: 88% **Nephropathy** *Entire cohort* - Abnormal UAE: 7% *Very young pre-pubertal-onset group* - Abnormal UAE: 4% **HT** *Entire cohort* - Any: 3% *Very young pre-pubertal-onset group* - Any: 0%
Schwab et al. 2006		
To ascertain the type and prevalence rate, age and sex distribution of cardiovascular risk factors in type 1 diabetic patients up to 26 years of age	**HT** Use of a sphygmanometer. Median value calculated from at least three	**HT** Systolic: 8.1% Diastolic: 2.5%

Cross-sectional design, documentation survey Germany and Austria; 195 centres 2003 - 2004 Sampled consecutive cases from a joint-national register; inclusion criteria: type 1 diabetes. n = 27,358 (n = 25,184 assessed for raised systolic blood pressure; n = 25,178 assessed for raised diastolic blood pressure; n = 27,358 assessed for HT treatment) Divided into pre-pubertal (0.25 - 11 years), pubertal (12 - 16 years) and young adulthood (17 - 26 years) based upon developmental stage Size of each cohort unclear *Age: 7.5 (2.5) years (pre-pubertal); 13.7 (1.4) years (pubertal); 18.5 (2.3) years (young adulthood); $p < 0.0001$ Male: 51.7% (pre-pubertal); 51.7% (pubertal); 52.5% (young adulthood); p value non-significant *Diabetes duration: 2.5 (2.3) years (pre-pubertal); 4.9 (3.6) years (pubertal); 8.2 (4.8) years (young adulthood);	measurements HT: Average systolic or diastolic blood pressure ≥ to the 95th percentile for age and sex. Values not provided for adults	Raised systolic BP: 5.8% (pre-pubertal); 7.4% (pubertal); 11% (young adulthood); $p < 0.0001$ Raised diastolic blood pressure: 3.9% (pre-pubertal); 3.2% (pubertal); 2.6% (young adulthood); $p < 0.0001$ Receiving anti-hypertensive medication: 2.1% (0.2% (pre-pubertal); 1.4% (pubertal); 4.8% (young adulthood)); $p < 0.0001$

p < 0.0001		
Steinbeck et al. 2015		
To determine if transition in type 1 diabetes is more effective with a comprehensive transition program compared with standard clinical practice Cross-sectional design Australia; number of adult centres unclear Data collected December 2007 - October 2009 Data only provided here in relation to participants attending the comprehensive transition program Patients recruited as they left paediatric diabetes services n = 14 (baseline and 12-month follow-up) Age: Median (IQR) 18.1 (17.3 - 18.8) years (baseline) Male: 50% *Diabetes duration: unclear	**DR** Unclear **Nephropathy** Unclear	**DR** *Baseline* - Any: 0% *12-month follow-up* - Any: 0% **Nephropathy** *Baseline* - Any: 0% *12-month follow-up* - Micro-albuminuria: 14.3%

ACR = Albumin-creatinine ratio. AER = Albumin excretion rate. BP = Blood pressure. DR = Diabetic retinopathy. HT = Hypertension. n = Number. OR = Odds ratio. UAE = Urinary albumin excretion. * = Mean (SD).

Appendix 5: Published paper

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BMC Endocrine Disorders

RESEARCH ARTICLE Open Access

Service usage and vascular complications in young adults with type 1 diabetes

Steven James[1], Lin Perry[2*], Robyn Gallagher[2], Julia Lowe[3], Janet Dunbabin[4], Patrick McElduff[4], Shamasunder Acharya[5] and Katharine Steinbeck[6]

Abstract

Background: Few studies have examined young adults with type 1 diabetes use of health services and the development of vascular complications. As part of the Youth Outreach for Diabetes (YOuR-Diabetes) project, this study identified health service usage, the prevalence and factors predictive of development of vascular complications (hypertension, retinopathy and nephropathy) in a cohort of young adults (aged 16–30 years) with type 1 diabetes in Hunter New England and the Lower Mid-North Coast area of New South Wales, Australia.

Methods: A cross-sectional retrospective documentation survey was undertaken of case notes of young adults with type 1 diabetes accessing Hunter New England Local Health District public health services in 2010 and 2011, identified through ambulatory care clinic records, hospital attendances and other clinical records. Details of service usage, complications screening and evidence of vascular complications were extracted. Independent predictors were modelled using linear and logistic regression analyses.

Results: A cohort of 707 patients were reviewed; mean (SD) age was 23.0 (3.7) years, with mean diabetes duration of 10.2 (5.8, range 0.2 - 28.3) years; 42.4% lived/ 23.1% accessed services in non-metropolitan areas.
Routine preventative service usage was low and unplanned contacts high; both deteriorated with increasing age. Low levels of complications screening were found. Where documented, hypertension, particularly, was common, affecting 48.4% across the study period. Diabetes duration was a strong predictor of vascular complications along with glycaemic control; hypertension was linked with renal dysfunction.

Conclusion: Findings indicate a need to better understand young people's drivers and achievements when accessing services, and how services can be reconfigured or delivered differently to better meet their needs and achieve better outcomes. Regular screening is required using current best practice guidelines as this affords the greatest chance for early complication detection, treatment initiation and secondary prevention.

Keywords: 'Service usage', Health services, 'Vascular complications', 'Prevalence', 'Prediction', 'Retinopathy', 'Nephropathy', 'Hypertension', 'Blood pressure', 'Young adults', 'Type 1 diabetes'

Background

Life expectancy and quality of life for people with type 1 diabetes are limited by the development of vascular complications such as nephropathy, retinopathy and hypertension, not least because such vascular changes lead to kidney failure and blindness, cardiac disease, stroke and limb amputations [1]. A systematic literature review of the prevalence and factors predictive of development of vascular complications in young adults with type 1 diabetes found few studies specifically recruited or even included representative samples, but that such complications were common even in youthful populations [2]. Few studies sought to determine factors predictive of development of these complications, but those most consistently reported, particularly amongst older groups, were diabetes duration, glycaemia and blood pressure (BP) control.

The onset of complications in early adulthood is particularly detrimental because of the loss of life years and restricted social participation at an age when it is more usually maximal. Early adulthood years are particularly

* Correspondence: Lin.Perry@uts.edu.au
[2]University of Technology, Sydney, 15 Broadway, Ultimo, New South Wales 2007, Australia
Full list of author information is available at the end of the article

important as this is when patterns of independent self-management are established. Young adults with type 1 diabetes may be particularly vulnerable to the development of complications as they may not receive disease-specific or age-appropriate care, and may disengage from the support of diabetes services when they leave the paediatric services they grew up with, at an age when adherence to diabetes self-management regimens is often reported as suboptimal [1,3-5]. Case note audit of young adults with type 1 diabetes accessing diabetes services in the state capital, a city and regional areas of New South Wales (NSW) in Australia demonstrated inadequate routine specialist care, poor self-management and frequent use of acute services for crisis management, particularly in regional areas [4]; however, sample sizes were small. Paucity of data on health service usage by young adults with type 1 diabetes for diabetes-related care, prevalence and predictors of vascular complications limits determination of the extent of the problem and hence appropriate service prioritisation.

This study aimed to identify the health service usage, prevalence and factors predictive of development of vascular complications (hypertension, retinopathy and nephropathy) in a cohort of young adults with type 1 diabetes in NSW.

Methods

This cross-sectional retrospective documentation survey was part of the Youth Outreach for Diabetes (YOuR-Diabetes) project, an Australian National Health and Medical Research Council funded service development and evaluation initiative for young adults with type 1 diabetes in the Hunter New England (HNE) and Lower Mid-North Coast region of NSW. Research partners were the Australian Diabetes Council and Hunter New England Health (HNEH), the public health service provider for approximately 850,000 residents across 130,000 square kilometres of NSW, including metropolitan Newcastle and regional/rural areas [6]. Specialist services for type 1 diabetes in the region and more widely have been described elsewhere [4,7,8].

Participants

Participants were young adults (aged 16–30 years) with type 1 diabetes as a primary condition. We collated our database from patient occasions of service with HNEH services from 2008 onwards, and audited contacts during 2010 and 2011. In Newcastle participants were identified through ambulatory care clinic records and Emergency Department (ED) and hospital attendances. In regional areas, records of Community Health, local diabetes educators and pathology services were also searched. We endeavoured to identify all young people with type 1 diabetes in the Local Health District, but recognised that our database may miss any who did not use state public health services, whose management and outcomes may be dissimilar to those reported.

Data collection

Paper and electronic health records - individual case notes and multi-disciplinary documentation - were reviewed and data extracted using methods developed previously [4], and the criteria listed in Table 1; 95% agreement was demonstrated between two experienced data extractors.

Planned and unplanned diabetes-related service contacts were the primary study outcomes: routine diabetes preventive care consultations with a doctor, diabetes nurse educator and/or dietitian; and unplanned presentations at any HNEH ED and/or acute hospitalisation for diabetes-related complaints. ED presentations resulting in hospital admission were solely recorded as hospitalisation.

Vascular complications were the secondary study outcomes. Data extracted included: BP measurements (number; values), ophthalmic examinations (number; documented absence/presence of retinopathy) and urinary albumin to creatinine ratio (ACR) measurements indicative of nephropathy (number; values): see Table 1 for definitions [9-11]. Data related to factors potentially predictive of development of vascular complications were also extracted. Socio-demographic data included age at diagnosis and area of residence [12] as these factors are recognized as impacting access and attendance at diabetes services [13,14].

Glycaemic control was determined by HbA1c assessments (number; values) classified in relation to an optimal target of less than or equal to 7.0% (53 mmol/mol) [9-11]. As the Australian Diabetes Society [15] advocates HbA1c be maintained at up to 8.0% (64 mmol/mol) for those with severe hypoglycaemic episodes or hypoglycaemia unawareness, mean HbA1c was further classified as equal to or above 8.0% (64 mmol/mol). Continuous Subcutaneous Insulin Infusion (CSII) use was noted as these devices have potential to improve diabetes management [16].

Data extracted for other factors shown to influence vascular disease risk were: smoking status, weight and height assessments, and Body Mass Index (BMI) calculations (number; values). BMI was firstly categorised as below 18.5 kg/m^2 (underweight), 18.5 - 24.9 kg/m^2 (on target), 25–29.9 kg/m^2 (overweight) and equal to or above 30 kg/m^2 (obese) [17].

Ethical approvals were obtained from Hunter New England, University of Newcastle and University of Technology, Sydney Human Research Ethics Committees.

Analyses

Data were entered into SPSS version 21 for analyses. Frequencies, means and standard deviations were used descriptively according to the level of the variable for service usage, vascular complications and potential predictive

Table 1 Study definitions of vascular complications

Complication	Complication present when:
Hypertension	Mean systolic or diastolic BP values ≥ 130/80 mmHg, respectively per annum, and/or prescription of anti-hypertensive medication
Retinopathy	Retinopathy documented
Nephropathy	At least one reported ACR measurement above laboratory threshold normal value

ACR: Albumin to creatinine ratio. *BP:* Blood pressure.

factors. Relationships were examined between groups with and without vascular complications using Chi-square and t-tests; Pearson's correlation coefficients were used between mean systolic and diastolic BP values and potentially linked characteristics such as planned, unplanned and total service contacts, mean HbA1c and BMI values, and diabetes duration. Associations between service usage, age and duration with diabetes were sought using multiple regression. Independent predictors of vascular complications were determined by logistic regression analysis, with separate models developed for hypertension, nephropathy and presence of any of the three vascular complications. For the analysis of these three models only, absence of evidence of documented vascular complications, laboratory values and smoking were treated as absence of that complication or potential predictive factor. No modelling was undertaken for retinopathy alone as reported cases were too few in number. Predictor variables were determined from the literature review and preliminary analyses of association. All three models included forced entry of the variables: any planned or unplanned health service contact, sex, metropolitan versus regional/rural residence, CSII use, smoking, mean HbA1c (used as a continuous variable and categorised as below, or equal to or above 8.0% (64 mmol/mol over the two years)), and diabetes duration [4,13,18-24]; hypertension was included as a variable in the analyses for nephropathy. BMI values were not included in regression analyses as assumptions of the analyses for a linear relationship were violated when used either as continuous or categorical variables. The critical level for retention in the model was set at 0.05. All assumptions of regression analysis were tested and met, including multi-collinearity.

Results

A total of 707 individual case records were identified, with data available for 682 and 707 cohort members in 2010 and 2011, respectively. At the end of the two-year study period the mean (SD) age of the cohort was 23.0 (3.7) years. The sexes were approximately equally represented with 384 (54.3%) male; 39 (5.6%) were documented as Aboriginal and/or Torres Strait Islander. Mean (SD, range) diabetes duration was 10.2 (5.8, 0.2 - 28.3) years, with median 3.0 years of adult service usage. A minority of 299 (42.4%) cohort members lived and 112 (23.1%) accessed services outside of a major city. With no clear record of insulin delivery method for 103 (14.6%) cohort members, 154 (21.8%) were current and 36 (5.1%) intermittent CSII users. The profiles of CSII and non-CSII users differed: CSII users were significantly older (mean age 22.9 versus 21.5 years; $t = 5.011$, $p < 0.001$); had diabetes longer (mean 11.2 versus 9.8 years; $t = 2.886$, $p < 0.004$); received more planned service contacts/two years (mean 11.5 versus 6.25 contacts; $t = 6.535$, $p < 0.001$); more HbA1c measurements/two years (mean 4.2 versus 2.6 measurements; $t = 6.353$, $p < 0.001$); more BP measurements/two years (mean 2.6 versus 1.5 measurements; $t = 5.523$, $p < 0.001$); and more ACR measurements/two years (mean 1.0 versus 0.7 measurements; $t = 3.291$, $p < 0.002$).

Service usage

Routine health service usage was low; 280 (41.1%) and 306 (43.5%) cohort members had no planned service contact recorded during 2010 or 2011. Where a planned service did occur, a median of six individual planned contacts (range 1–52) with healthcare providers (i.e. consultations with doctors, nurses and dieticians) were undertaken across the two-year study period.

Unplanned service contacts were common; 308 (45.2%) and 326 (46.1%) members had at least one diabetes-related ED presentation and/or hospitalisation during 2010 or 2011; of those who had any unplanned contact an overall median of two contacts (range 1–22) occurred. Unplanned contacts occurred more frequently amongst those who had evidence of retinopathy or nephropathy: for example, 90% of those who had retinopathy versus only 61.4% of those without documented retinopathy had at least one unplanned service contact. A median of eight (range 1–62) planned/unplanned contacts were reported, with 178 and 184 (26.1% in each year) cohort members having no reported service contact, planned or unplanned, and 87 (12.8%) having no service contact over the two years.

There was a significant negative correlation between age and total number of planned contacts/two years (Pearson $R = -0.339$, $p < 0.001$) and significant but weaker association with duration since diagnosis ($R = -0.168$, $p < 0.001$; overall model fit $R^2 = 0.120$). Multiple regression analysis demonstrated significant relationships between increasing age and fewer planned contacts (Beta = –0.321, $p < 0.001$), whilst the relationship with diabetes duration was not significant (overall model fit $R^2 = 0.118$). A similar pattern was seen

with unplanned service usage (Beta = −0.104, p < 0.019); whilst still significant, this was much weaker, i.e. increasing age was more strongly linked with reducing use of preventive care than acute service usage.

Vascular complications

Low levels of screening and/or documentation were recorded but evidence indicated presence of co-morbid disease (Table 2). The majority had no documented BP measurement, ophthalmic examination or ACR measurement during either 2010 or 2011, respectively. Prescription records were unavailable for 269 (38%) and a prescription for anti-hypertensive medication was documented for 72 (10.2%). A total of 201 (48.4%) participants were classified as hypertensive on the basis of at least one documented elevated BP measurement or anti-hypertensive medication prescription. At least one documented BP measurement equal to or above 130/80 mmHg was reported in 35 (48.6%) cohort members prescribed anti-hypertensive medication, across the study period.

Of those who had a documented ACR measurement, 137 (40.1%) had two or more and 17 (12.4%) of these had two or more above the threshold value. Those who used CSII were reported to have some form of vascular complication (hypertension, retinopathy and/or nephropathy) at a similarly high frequency to non-CSII users (55.6% affected versus 53.8%), but overall nearly 40% of the sample were eliminated from these analyses due to incomplete data (n = 428 included).

Vascular risk factors

Low levels of documented risk factors were also evident (Table 3). Of those who had any HbA1c measurement a median of three measurements were documented (range 1–12) across the two year study period. In cohort members identified as having hypertension, retinopathy and/or nephropathy, a minority of 67 (36.6%), 6 (30.0%) and 15 (26.8%) had mean recorded HbA1c below 8.0% (64 mmol/mol), respectively.

Although records of smoking were incomplete for 387 (54.7%), 94 (13.3%) were reported as current smokers. No weight was recorded for 38.8%, and a median one weight assessment per person (range 1–11) was documented. Height measurement was not documented for 259 (36.6%).

Associations between risk factors and vascular complications

Cohort members were more likely to have documented hypertension if they were male (55.7% versus 41.0%, $Chi^2 = 9.02$, p = 0.003) or had none rather than any unplanned service contact (55.4% versus 44.3%, $Chi^2 = 9.36$, p < 0.003). Higher mean systolic BP values were linked to older age (r = 0.339, p < 0.001), longer diabetes duration (r = 0.168, p < 0.002), (unsurprisingly) higher mean diastolic values (r = 0.639, p < 0.001), greater BMI values (r = 0.210, p < 0.004), fewer planned (r = −0.167, p < 0.002), unplanned (r = −0.169, p < 0.001) and total service contacts (r = −0.201, p < 0.001).

Similar associations were seen with mean diastolic BP values, with higher recordings linked to older age (r = 0.302, p < 0.001), longer diabetes duration (r = 0.214, p < 0.001), greater mean HbA1c (r = 0.178, p < 0.001) and fewer planned (r = 0.109, p < 0.033) and total service contacts (r = −0.106, p < 0.038).

Cohort members who had retinopathy in comparison to those who did not were significantly older (mean age

Table 2 Screening for vascular complications and associated outcomes

Variable	2010	2011
	Number (%)	*Number (%)*
BP measurements documented	(n = 682)	(n = 707)
At least one	313 (45.9)	306 (43.3)
Mean systolic/diastolic BP	(n = 313)	(n = 306)
≥ 130/80 mmHg	106 (33.9)	94 (30.7)
Ophthalmic examinations documented	(n = 682)	(n = 707)
At least one	95 (14)	85 (12)
Ophthalmic examination reported outcome	(n = 95)	(n = 85)
Retinopathy	13 (13.7)	8 (9.4)
ACR measurements documented	(n = 682)	(n = 707)
At least one	222 (32.6)	218 (30.8)
ACR measurements above threshold value^	(n = 219)	(n = 218)
At least one	33 (15.1)	35 (16.1)

ACR: Albumin to creatinine ratio. *BP:* Blood pressure.
^ Three cohort members excluded from analysis for 2010 as measurement undertaken but result unknown.

Table 3 Vascular disease risk factors

Variable	2010	2011
	Number (%)	*Number (%)*
HbA1c documented	(n = 682)	(n = 706)
At least one	422 (61.9)	425 (60.2)
HbA1c value (s) ≤ 7.0% (53 mmol/mol) documented in those with ≥ 1 recorded	(n = 422)	(n = 425)
At least one	104 (24.6)	95 (22.4)
HbA1c value (s) ≥ 8.0% (64 mmol/mol) documented in those with ≥ 1 recorded	(n = 422)	(n = 425)
At least one	295 (69.9)	293 (68.9)
Mean HbA1c	(n = 422)	(n = 425)
≥ 8.0% (64 mmol/mol)	260 (61.6)	269 (63.3)
Weight documented	(n = 683)	(n = 707)
At least one	340 (49.8)	345 (48.8)
Mean BMI	(n = 272)	(n = 255)
< 18.50 kg/m^2	5 (1.8)	4 (1.6)
18.50 - 24.99 kg/m^2	160 (58.8)	137 (53.7)
≥ 25–29.99 kg/m^2	69 (25.4)	74 (29)
≥ 30 kg/m^2	38 (14)	40 (15.7)

BMI: Body Mass Index

24.1 versus 21.7 years, t = −3.053, df 158, p < 0.003), had longer diabetes duration (mean 14.1 versus 11.0 years; t = −2.531, df 143, p < 0.021) and more unplanned service contacts over the two-year period (mean 4.4 versus 1.8 contacts; t = 2.885, df 22, p < 0.009).

Cohort members who had any recorded ACR measurement above threshold values in comparison to those who did not were significantly older (mean 23.2 versus 22.0 years; t = −2.381, df 332, p < 0.018) and had significantly higher mean HbA1c values across the two-year period (9.4% versus 8.6%; t = −3.174, df 327, p < 0.002). They were more frequently documented with hypertension (68.2% versus 42.0%, $Chi^2 = 10.2$, p < 0.001).

Independent predictors of vascular complications

Logistic regression analysis revealed that cohort members were more likely to have hypertension (model $Chi^2 = 45.34$, df 7, p < 0.001) if they had no (rather than any) health service contact (OR 0.21, 95% CI 0.1 - 0.51, p = 0.001), any use of CSII (OR 1.8, 95% CI 1.2 - 2.7, p = 0.004) or a longer diabetes duration (each year, OR 1.05, 95% CI 1.01 - 1.09, p = 0.006). The odds of having nephropathy (model $Chi^2 = 42.95$, df 8, p < 0.001) were increased more than three times by having hypertension (OR 3.19, 95% CI 1.66 - 6.15, p < 0.001) and having a mean HbA1c at or greater than 8.0% (64 mmol/mol) (OR 3.59, 95% CI 1.67 - 7.74, p = 0.001) (Table 4).

The likelihood of documented hypertension, retinopathy and/or nephropathy (model $Chi^2 = 58.02$, df 7, p < 0.001) increased with absence of health service contact (OR 0.17, 95% CI 0.07 - 0.41, p < 0.001), with any CSII use (OR 1.78, 95% CI 1.19 - 2.64, p = 0.005), a mean HbA1c equal to or above 8.0% (64 mmol/mol) (OR 1.64, 95% CI 1.13 - 2.38, p = 0.01) and longer diabetes duration (each year, OR 1.05, 95% CI 1.02 - 1.09, p = 0.003) (Table 4). Statistical significance was attenuated or lost for these variables when mean recorded values for HbA1c and BP were employed.

Discussion

The study findings are broadly representative across metropolitan, regional and rural Australia as they present data from 707 young adults of a potential 830 people with type 1 diabetes within this age band registered on the National Diabetes Services Scheme (personal communication), a 'best option' source for population figures for this mobile group. Findings demonstrated young adults with type 1 diabetes in this region of NSW at risk of poor health outcomes. Low attendance for preventive care, and shortcomings according to international standards [9-11] in the screening they received when they attended, reduced sample size for many analyses; consequently some associations, whilst statistically significant, showed low explanatory power. Nonetheless, data indicated inadequate access/uptake of routine preventive care and increasing age of patients accompanied by a more significant pattern of reducing use of routine preventive care than use of acute services for diabetes crisis management.

Data were indicative or suggestive of co-morbid disease, consistent with systematic review findings [2]. Where assessed, one in six cohort members had at least one recorded episode of microalbuminuria and as many

Table 4 Predictors of hypertension, nephropathy and any vascular complication (hypertension, retinopathy and/or nephropathy)

Predictor	Hypertension			Nephropathy			Hypertension, retinopathy and/or nephropathy		
	B	95% CI	p value	*B*	95% CI	p value	*B*	95% CI	p value
Any CSII use	1.8	1.2 - 2.7	0.004	1.06	0.54 - 2.08	0.877	1.78	1.19 - 2.64	0.005
Male	1.42	0.97 - 2.08	0.069	0.58	0.28 - 1.03	0.062	1.16	0.8 - 1.68	0.424
Mean HbA1c ≥ 8%	1.42	0.96 - 2.09	0.077	3.59	1.67 - 7.74	0.001	1.64	1.13 - 2.38	0.01
Smoking	1.34	0.91 - 1.96	0.135	1.2	0.63 - 2.29	0.572	1.3	0.9 - 1.88	0.17
Diabetes duration	1.05	1.01 - 1.09	0.006	0.99	0.93 - 1.06	0.831	1.05	1.02 - 1.09	0.003
Metropolitan residence	0.92	0.63 - 1.37	0.69	1.184	0.6 - 2.32	0.623	0.97	0.66 - 1.42	0.868
No reported service contact	0.21	0.1 - 0.51	0.001				0.17	0.07 - 0.41	< 0.001
Hypertension	N/A			3.19	1.66 - 6.15	0.001	N/A		
Constant	0.16		< 0.001	0.3		< 0.001	0.21		< 0.001
Model Statistics	$Chi^2 = 45.34$, df 7, n550, $p < 0.001$			$Chi^2 = 42.95$, df 8, n550, $p < 0.001$			$Chi^2 = 58.02$, df 7, n550, $p < 0.001$		

CSII: Continuous Subcutaneous Insulin Infusion. *N/A:* Not applicable.
No modelling undertaken for retinopathy independently or analyses of no health service contact as a predictor of nephropathy as too few cases.

as one in three had a mean recorded systolic or diastolic BP equal to or above 130 mmHg and/or 80 mmHg, respectively; almost one in two were affected when medication for hypertension was included. One in nine had documented retinopathy; less than demonstrated for young adults in NSW between 1990–2000 [25], but consistent with more recent NSW adolescents' data from 2005–2009 [26]. Whilst a reduction in retinopathy prevalence over time may have been related to changes in diabetes management following the definitive Diabetes Control and Complications Trial [22] which made glycaemic control central, low levels of screening potentially under-estimates the true level of retinopathy in this cohort; also hypertension and nephropathy. Collectively, these data are cause for concern, indicating low use of preventive services reducing with increasing age accompanied by early onset of co-morbid disease, increased risk of impaired quality of life and premature mortality.

Despite guidelines recommending use of angiotensin converting enzyme or angiotensin 2 receptor blockers even in children, few of this cohort were in receipt of treatment or treated to target. Only one in ten were documented as prescribed anti-hypertensive medication and of those that were, two in three had mean BP equal to or above 130/80 mmHg across the study period; potentially indicating missed opportunities for disease modification. This is particularly regrettable since elsewhere rates of anti-hypertensive prescription have been reported as increasing significantly, to 34.2% in 2007 [27].

Internationally accepted standards for glycaemia management were largely not met [9-11], with inadequate HbA1c monitoring and two-thirds of cohort members with at least one measurement within the two-year period having mean HbA1c at or greater than 8.0% (64 mmol/mol). However, the Epidemiology of Diabetes Interventions and Complications (EDIC) Study [28] found similar HbA1c values, increasing in adolescents in the intensive treatment group (from 8.1% to 8.4%) and decreasing (but still elevated) in the conventional treatment group (from 9.8% to 8.5%) after study end. These data suggested it may be difficult to maintain HbA1c values under 8.0% in young people outside a clinical trial. Data from this location in NSW appear consistent with this conclusion.

Findings regarding the use of CSII were noteworthy. Whilst CSII users received overall significantly greater planned service use and assessments, hypertension and any vascular complication occurred more frequently in association with any usage of CSII. Results should be viewed with caution due to missing data but whilst findings were not in line with some studies [16] they were consistent with a previous NSW study which showed that while CSII use doubled during the study period, HbA1c in users deteriorated, rising from 8.4% to 8.6% [3]. It is tempting to speculate that perhaps people with poor control of blood glucose, and associated hypertension, may have been started on CSII in an attempt to improve control, but most of these young people were likely to have commenced use of CSII as children. Education at initiation of CSII for children is primarily to parents/responsible adults. If the child/teen was not targeted for education pre-transition from paediatric care, deficiencies in CSII knowledge were not likely to have been picked up or rectified if the young adult did not have a good relationship with a pump-specialist. Subsidised access to CSII combined with greater access to specialist support for children has resulted in expansion of CSII use particularly amongst children [29], with trends to start CSII use at diagnosis gaining favour. This

raises the question how prepared for independent self-management such CSII users are, as they move into adulthood and lose access to paediatric specialist services. Further research is needed to examine whether and how insulin pumps may deliver on their promise of improved diabetes control for people with type 1 diabetes [29]. Given the cost in provision of CSII and the human resources required to support pump users, the possibility that they may not improve outcomes is too important to ignore. Whilst there may be many reasons for a decline in management of diabetes and its complications in young adults using insulin pumps, one might be that stretched diabetes teams lack adequate specialist resources to provide the more complex and time consuming support needed to optimise results.

Over half of this cohort resided in a major city, and half of those who did not travelled there to access specialist diabetes services. Inadequate access to routine specialist care in regional areas may have contributed to low uptake and increasing attrition with age from routine preventive care services, infrequent screening and suboptimal outcomes. Geographical and socioeconomic factors have been cited as major issues in access to diabetes services, and strong predictors of attendance [14]. Improved diabetes management has been shown by those who maintain contact and relationships with their diabetes healthcare teams [13]. However, this may be a simplistic interpretation. Patterns of use of planned and unplanned service contacts suggest these young people were not routinely or systematically using preventive services to support their self-care; instead, emergency and acute services appeared to be being used with almost half of cohort members having at least one diabetes-related ED presentation and/or hospitalisation in 2010 and similarly in 2011. Emergency hospital admission can be seen as an indicator of poor quality of diabetes care [30], with concerns raised at the education provided by healthcare staff in this situation [31].

A chief limitation of this study was use of data originally collected as patient clinical healthcare records; all such studies are forced to rely on professional and legal accountability for clinical record-keeping, and the value attached to record quality in such situations of life-long care. Nonetheless study data will have been affected by factors affecting the quality of clinical record keeping. Whilst there was potential for Berkson's bias on results, lack of access to General Practice (GP) or private practice data mean their service episodes were not reflected in these findings except as secondary report within case notes. However, few local GPs offered specialist support for type 1 diabetes; our previous qualitative study with this population reported their experience of GP diabetes care as predominantly age-inappropriate and non-specialist, and private endocrinologists as unaffordable [32]. Thus this may not have materially affected findings. The two-year time period of the study did not allow for trends across time, and the representative nature of these data can only be estimated by comparison to the earlier study, which revealed that little had changed over time [4]. Study co-morbidity definitions (specifically hypertension and nephropathy) were somewhat simplistic and data were not collected about acute illness and other co-morbidities that may affect screening and disease management. Furthermore, considering the high prevalence of type 2 diabetes in Aboriginal and/or Torres Strait Islander populations [33,34] a few may have been documented incorrectly with type 1 diabetes based on insulin administration. Nonetheless, the strengths of this study lie with the size of the cohort, the geographical size and range from which the cohort derives, and its near-complete population sampling within this under-researched age group.

Conclusion

Findings flag a need to better understand young people's drivers and achievements when accessing services, and how services can be reconfigured or delivered differently to engage young people with age-appropriate care that better meets their needs to achieve improved outcomes and defer development of complications. In line with national guidelines [10], most type 1 diabetes should be managed by a multidisciplinary specialist health-care professional team, including in the rural and regional setting, where diabetes care may be provided by a locally based paediatrician, physician and/or GP on a shared care basis with a multidisciplinary diabetes care team. In many locations this will require reconfiguration and appropriate apportionment of resourcing of multidisciplinary teams in both urban and rural areas, particularly in view of the highly specialist needs of the increasing number of people with diabetes using CSII. Health professionals need to work out ways to enable regular screening to be performed using current best practice guidelines as this affords the greatest chance for early complication detection and hence for initiation of treatment and secondary prevention.

Competing interests
The authors declare that they have no competing interests.

Author's contributions
Study proposal developed by LP, JL, JD, PM, SA and KS. Data collected by JD. Analyses conducted by SJ, LP, RG and PM. Paper drafted by SJ, LP, RG and JL, revised and agreed by all authors. All authors read and approved the final manuscript.

Author's information
SJ: RN, CDE Doctoral student, Faculty of Health, University of Technology, Sydney, Australia.
LP: PhD, MSc, RN Professor of Nursing Research and Practice Development, Prince of Wales Hospital, Sydney and Sydney Eye Hospitals, Faculty of Health, University of Technology, Sydney, Australia.

RG: PhD, MN, RN Associate Professor Chronic and Complex Care, and Director, Research Students, Faculty of Health, University of Technology, Sydney, Australia.
JL: MBChB, MRCP, FRCP, MMedSci Associate Professor, University of Toronto, Canada.
JD: PhD, BAg Research Assistant, University of Newcastle, Australia.
PM: PhD, BMath, Grad Dip Med Stats Associate Professor, University of Newcastle, Australia.
SA: MBBS, FRACP Staff Specialist Endocrinologist, Lead Clinician, Diabetes Service, Hunter New England Local Health District, Australia.
KS: MBBS, FRACP, PhD Medical Foundation Chair in Adolescent Medicine, University of Sydney, Australia.

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Author details
[1]Huntsville District Memorial Hospital, 100 Frank Miller Drive, Huntsville, Ontario P1H 1H7, Canada. [2]University of Technology, Sydney, 15 Broadway, Ultimo, New South Wales 2007, Australia. [3]Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Toronto, Ontario M4N 3M5, Canada. [4]University of Newcastle, University Drive, Callaghan, Newcastle, New South Wales 2308, Australia. [5]Hunter New England Local Health District, New Lambton Heights, New South Wales 2305, Australia. [6]University of Sydney, Darlington, Sydney, New South Wales 2008, Australia.

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doi:10.1186/1472-6823-14-39
Cite this article as: James *et al.*: Service usage and vascular complications in young adults with type 1 diabetes. *BMC Endocrine Disorders* 2014 **14**:39.

Appendix 6: Human research ethics approval

NSW GOVERNMENT Health
Hunter New England
Local Health District

28 June 2012

Associate Professor J Lowe
Hunter Area Diabetes Service
David Maddison Building
University of Newcastle

Dear Professor Lowe,

Re: A Young Adult Outreach Service for Type 1 Diabetes Mellitis in Rural NSW (07/09/19/4.01)

HNEHREC Reference No: 07/09/19/4.01
NSW HREC Reference No: 07/HNE/29
NSW SSA Reference No: 07/HNE/30

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* (National Statement) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment requests:

- For the addition of Ms Maxine Ambrose as co-investigator at Narrabri Community Health Centre;
- For the addition of Mr Steven James as student researcher;
- For the removal of Ms Kirsty McDonald as student researcher; and
- For Training in and read only access to CHIME by the project research assistant

For the protocol: **A Young Adult Outreach Service for Type 1 Diabetes Mellitis in Rural NSW**

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of **3** years from the date of the approval letter of your initial application, after which a renewal application will be required if the protocol has not been completed. The above protocol is approved until **January 2014.**

Approval has been granted for this study to take place at the following sites:

- **Armidale Community Health, NSW**
- **Foster Community Health, NSW**
- **Narrabri Community Health, NSW**

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email:hnehrec@hnehealth.nsw.gov.au
http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

- **Moree Community Health, NSW**
- **Tamworth Community Health, NSW**
- **Taree Community Health, NSW**
- **Prince of Wales Hospital, NSW**
- **Sydney Children's Hospital, NSW**

The *National Statement on Ethical Conduct in Human Research (2007)* which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- A report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is **January 2013.** A proforma for the annual report will be sent two weeks prior to the due date.

- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

- All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    - any serious or unexpected adverse events
        - Adverse events, however minor, must be recorded as observed by the Investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the Investigator or his deputies considers the event to be related to the trial substance or procedure.

        - Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.

        - Copies of serious adverse event reports from other sites should be sent to the Hunter New England Human Research Ethics Committee for review as soon as possible after being received.

        - Serious adverse events are defined as:

            - Causing death, life threatening or serious disability.
            - Cause or prolong hospitalisation.
            - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.

    - Unforeseen events that might affect continued ethical acceptability of the project

- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand, the Manager, Research Ethics and Governance Unit as soon as possible.

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email:hnehrec@hnehealth.nsw.gov.au
http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website:
Internet address: http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Please quote **07/09/19/4.01** in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Associate Professor M Parsons
Chair
Hunter New England Human Research Ethics Committee

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email:hnehrec@hnehealth.nsw.gov.au
http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

HUMAN RESEARCH ETHICS COMMITTEE

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	**Conjoint Associate Professor Julia Lowe**
Cc Co-investigators / Research Students:	**Professor Dimity Pond** **Doctor Sham Acharya** **Doctor Patrick McElduff** **Ms Elizabeth Nunn** **Doctor Lin Perry** **Associate Professor K Steinbeck** **Mrs Angela Blair** **Ms Maxine Ambrose** **Mr Steven James**
Re Protocol:	**A young adult outreach service for Type 1 Diabetes Mellitus in rural NSW**
Date:	**16-Jul-2012**
Reference No:	**H-634-1107**

Thank you for your **Variation** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to a variation to the above protocol.

Variation to;

Add Ms Maxine Ambrose and Mr Steven James to the research team;

Remove Ms Kirsty McDonald from the research team;

Training in and read only access to CHIME by the project research assistant.

Your submission was considered under **Expedited Review of External Approval** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective **12 -Jul-2012**.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request.

Professor Allyson Holbrook
Chair, Human Research Ethics Committee

For communications and enquiries:
Human Research Ethics Administration

Research Services
Research Integrity Unit
HA148, Hunter Building
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 18999
F +61 2 492 17164
Human-Ethics@newcastle.edu.au

Linked University of Newcastle administered funding:

Funding body	Funding project title	First named investigator	Grant Ref
BellBerry Limited/Near Miss(**)	Evaluation of a systems navigation model of transition care for non-metropolitian young adults with type 1 diabetes	Perry Lin,	G0900223
NHMRC (National Health & Medical Research Council)/Partnership Projects(**)	Implementation and Evaluation of a Systems Navigation Model of Transition and Care for Non-Metropolitan Young Adults with Type 1 Diabetes: Youth OutReach for Diabetes (YOuR-Diabetes) Cluster-Randomised Controlled Trial in Hunter New England	Perry Lin,	G1000536
NSW Ministry of Health/Project Grant (**)	A Young adult Outreach Service for Type 1 Diabetes Mellitus in Rural NSW	Perry Lin,	G0187333

Appendix 7: Published paper

Received: 19 July 2016 | Revised: 11 September 2016 | Accepted: 5 October 2016

DOI 10.1111/jep.12670

WILEY Journal of Evaluation in Clinical Practice
International Journal of Public Health Policy and Health Services Research

ORIGINAL ARTICLE

Young people with type 1 diabetes mellitus: Attitudes, perceptions, and experiences of diabetes management and continuous subcutaneous insulin infusion therapy

Lin Perry PhD MSc RN[1,3] | Steven James PhD Candidate RN CDE[2] | Katharine Steinbeck MBBS FRACP PhD[4,5] | Janet Dunbabin PhD BAgSc[6] | Julia Lowe MBChB FRCP MMedSci[7,8]

[1] Professor, Faculty of Health, University of Technology Sydney, Ultimo, New South Wales, Australia

[2] PhD Candidate, Faculty of Health, University of Technology Sydney, Ultimo, New South Wales, Australia

[3] Professor, South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick, New South Wales, Australia

[4] Professor, Sydney Medical School, University of Sydney, Sydney, New South Wales, Australia

[5] Professor, Academic Department of Adolescent Medicine, The Children's Hospital at Westmead, Westmead, New South Wales, Australia

[6] Doctor, Faculty of Health and Medicine, University of Newcastle, Callaghan, New South Wales, Australia

[7] A/Professor, Department of Medicine, University of Toronto, Toronto, Ontario, Canada

[8] A/Professor, Division of Endocrinology and Metabolism, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada

Correspondence
Steven James, Faculty of Health, University of Technology Sydney, 15 Broadway, Ultimo, New South Wales 2007, Australia.
Email: stevenjames_76@yahoo.co.uk

Abstract

Rationale, aims, and objectives Continuous subcutaneous insulin infusion (CSII; insulin pump) use is increasing. However, there is little information about how this technology is used compared with other insulin delivery methods (ie, injections) by young people with type 1 diabetes mellitus in Australia. This study explored young people's attitudes, perceptions, and experiences with diabetes management comparing those using with those not using CSII, and proportions likely to transition to adult services requiring initiation and/or support for CSII use.

Methods A survey was undertaken of young people (aged 12 to 18 years) with type 1 diabetes mellitus and their parents/guardians living in Hunter New England, Australia, using a questionnaire designed to collect quantitative, descriptive, and demographic data. Most questions were based on previously developed and validated instruments. In total, 107 respondents returned partially or fully completed questionnaires.

Results Respondents had positive attitudes and perceptions of their self-efficacy and diabetes management, but were moderately disturbed by their diabetes and reported experiencing suboptimal management outcomes. Patterns of associations were demonstrated between knowledge, attitudes, and experiences of diabetes modeled by regression analysis. There were no statistically significant differences in responses between users and nonusers of CSII. Over 40% indicated their intention to use the technology as adults.

Conclusions Opportunities for enhanced diabetes service support were clear, and CSII did not appear to be used to its full potential. Service redesign could enhance support for this young population using all preferred insulin delivery methods and should align to patients' goals and preferences to maximize service and patient gain.

KEYWORDS

attitude, continuous subcutaneous insulin infusion systems, experiences, health transition, pediatric, type 1 diabetes mellitus, young people

Appendix 8: Questionnaire

Insulin pump therapy for young people with Type 1 diabetes

Researchers in Newcastle and Sydney and from Diabetes Australia New South Wales are conducting a study about insulin pump services for young people with type 1 diabetes. You are invited to take part in this project by completing this survey. You will find more information in the Information Statements sent with it. It is ok to fill this in by yourself, to have some help from your parents, or for your parents to fill it in. We will ask you to tell us how it was filled in at the end.

To answer questions, please put a X in the [ ] or write your answer on the line

First some questions about you

1. Are you: Male [ ] Female [ ]

2. What is your date of birth? ___/___/_____

3. When did you find out you had diabetes? Year _____ Month _____

4. Your post code where you live now is: _____

5. Are you a full-time student? Yes [ ] No [ ]

6. Do you live at home with your family? Yes [ ] No [ ]

7. Do you have Aboriginal or Torres Strait Islander heritage?

No [ ] Yes, Aboriginal [ ] Yes, Torres Strait Islander [ ]

8. How do you take your insulin? Is this by:

Pump	[ ]
One or two injections every day	[ ]
3 or 4 injections every day	[ ]
More than 4 injections every day	[ ]
Other (please explain)	

_____

9. What is/are the name(s) of the insulin(s) that you take?

_____

_____

10. Do you inject using:

Needles and syringes	[ ]
Pens	[ ]
Both	[ ]
Not applicable	[ ]

11. How often do you usually measure your blood sugar levels?

Every day	[ ]
Less than once a day	[ ]
More than twice a day	[ ]
More than 4 times a day	[ ]

12. What is your most recent HbA1c reading?

___.__% or Don't know [ ]

13. How does this compare with usual readings?

Higher	[ ]	Lower	[ ]
About the same	[ ]	Don't know	[ ]

14. About how tall are you? _____ (cm)

15. What is your weight, approximately? _____ (kg)

16. Thinking about the last 12 months, how many times have you had a diabetes problem that has caused you to:

Go to the Emergency Department, but go home afterwards _____

Stay in hospital _____

17. Thinking about the last month, on average how many hypos did you have in a week? _____

18. Have you ever had any hypos and needed someone else to give you sugar and/or glucagon injection?

Yes [ ] No [ ]

If yes, how many? _____

19. Have you had a diabetes eye check-up in the last year? Yes [ ] No [ ]

20. Have you had a diabetes urine check-up in the last year? Yes [ ] No [ ]

The next questions ask about your diabetes management and how you feel about it

Please put an X on the line to indicate where you feel you are between what it says at each end

22. I take care of my diabetes independently (by myself) if needed:

l_____l_____l_____l_____l

Never All the time

23. I change my insulin dose independently (by myself) if needed:

l_____l_____l_____l_____l

Never All the time

24. Thinking about how much I know about my diabetes:

l_____l_____l_____l_____l

Nothing Everything

25. I am disturbed by my diabetes:

l_____l_____l_____l_____l

Never All the time

This question reflects how you feel about your diabetes management

Please put an X in the box on each row that reflects how you feel about your diabetes management

26.	**Strongly disagree**	**Disagree**	**Neither agree or disagree**	**Agree**	**Strongly Agree**
a. It is difficult for me to find effective solutions for problems that occur with managing my diabetes					
b. Efforts to change things I don't like about my diabetes don't work					
c. I handle myself well with respect to my diabetes					
d. I am able to manage things related to my diabetes as well as most other people					
e. I succeed in the things I do to manage my diabetes					
f. Typically, my plans for managing my diabetes don't work out well					
g. No matter how hard I try, managing my diabetes doesn't turn out the way I would like					
h. I'm generally able to achieve what I plan to do with respect to managing my diabetes					

The next questions are about insulin pumps. There are two sections - one for people who have NEVER used a pump, and another for people who HAVE used a pump at some point (or are using one now)

If you run out of space please use the spare sheet of paper at the end. Don't forget to put the question number!

27. Have you ever been on an insulin pump?

Yes [ ] No [ ]

If you have been on a pump, turn to the next page

If you answered No to ever having been on a pump

28. Are you considering going on to an insulin pump in the future?

Yes [ ] No [ ]

29. What would make you more likely to go on a pump?

_____

_____

_____

30. What would make it less likely that you would choose to go on a pump?

_____

_____

_____

31. Do your parents want you to go on a pump?

Yes [ ] No [ ] Not sure [ ]

Please go to Q37

If you answered YES to having ever been on a pump

32. How old were you when you first used an insulin pump? ____ years ____ months

33. Has the pump ever broken down? Yes [ ] No [ ]

33a. If yes, please tell us about it:

_____

_____

_____

34. Have there been any other times when you have decided not to use it?

Yes [ ] No [ ]

34a. If you answered yes, please tell us about it:

_____

_____

_____

35. If you stopped using you pump completely, did you subsequently go back to using it?

Yes [ ] No [ ]

35a. If you answered yes, please tell us about it:

_____

_____

_____

36. Do you use an insulin pump now? Yes [ ] No [ ]

37. Do you intend to use an insulin pump when you move to adult diabetes services?

Yes [ ] No [ ] Haven't thought about it [ ]

Please rate your experiences with using the insulin pump by putting an X in the box that is closest to the way you feel

38a. How satisfied are you overall with the pump?

Very unsatisfied	[ ]	Unsatisfied	[ ]	Somewhat satisfied	[ ]	Satisfied	[ ]	Very satisfied	[ ]

38b. How prepared were you for your transition to the pump?

Very unprepared	[ ]	Somewhat unprepared	[ ]	Somewhat prepared	[ ]	Prepared	[ ]	Very prepared	[ ]

38c. How easy is the pump to use?

Not at all easy	[ ]	Somewhat easy	[ ]	Easy	[ ]	Very easy	[ ]	Extremely easy	[ ]

38d. How difficult is the pump to use compared to what you expected?

Much harder	[ ]	Harder	[ ]	About what you expected	[ ]	Easier	[ ]	Much easier	[ ]

Please indicate any changes in your life in the following areas as a result of using the insulin pump by putting an X in the box on each row that is closest to the way you feel

39.	**Much worse**	**Worse**	**About the same**	**Better**	**Much better**
a. Flexibility of meal schedules					
b. Flexibility of sleep schedules					
c. Food variety					
d. Worry related to diabetes					
e. Level of your responsibility					
f. Knowledge about diabetes					

40. Please list any changes in your life as a result of using the insulin pump

_____

_____

_____

41. What are the most challenging aspects of using a pump?

_____

_____

_____

42. What help or advice would you offer to other people considering using an insulin pump?

_____

_____

_____

If you would like to make further comments, please do on the blank page. Thank you.

This survey was filled out by:

Young person/teen alone	[ ]
Parent(s) alone	[ ]
Young person and parent(s)	[ ]

If you would like to talk to us, if there is anything you do not understand, or you have questions, please contact the researchers by phone, text or email - details below.

Janet Dunbabin (Researcher)
(02) 4913 8822
Yourdiabetes@live.com.au

Helen Phelan (Researcher)
(02) 4913 8822
Helen.Phelan@hnehealth.nsw.gov.au

Lin Perry (Chief Investigator)
(02) 94913 8822
Lin.Perry@newcastle.edu.au

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

This is your blank piece of paper, to use if you run out of space answering the questions. Please add relevant question number.

Appendix 9: Published paper

Received: 24 August 2016 | Revised: 15 December 2016 | Accepted: 16 December 2016

DOI 10.1111/jep.12703

WILEY Journal of Evaluation in Clinical Practice
International Journal of Public Health Policy and Health Services Research

ORIGINAL ARTICLE

Supporting patients with type 1 diabetes using continuous subcutaneous insulin infusion therapy: Difficulties, disconnections, and disarray

Lin Perry PhD MSc RN[1] | Steven James PhD Candidate RN CDE[2] |
Robyn Gallagher PhD MN RN[3] | Janet Dunbabin PhD BAgSc[4] |
Katharine Steinbeck MBBS FRACP PhD[5] | Julia Lowe MBChB FRCP MMedSci[6]

[1]Professor, Faculty of Health, University of Technology Sydney/South Eastern Sydney Local Health District, Prince of Wales Hospital, Randwick, Australia

[2]PhD Candidate, Faculty of Health, University of Technology Sydney, Ultimo, Australia

[3]Professor, Charles Perkins Centre, University of Sydney, Sydney, Australia

[4]Doctor, Faculty of Health and Medicine, University of Newcastle, Callaghan, Australia

[5]Professor, Sydney Medical School, University of Sydney/Academic Department of Adolescent Medicine, The Children's Hospital at Westmead, Westmead, Australia

[6]Associate Professor, Department of Medicine, University of Toronto/Division of Endocrinology and Metabolism, Sunnybrook Health Sciences Centre, Toronto, Canada

Correspondence
Steven James, Faculty of Health, University of Technology Sydney, Broadway, Ultimo New South Wales 2007, Australia.
Email: stevenjames_76@yahoo.co.uk

Funding information
New South Wales Institute for Rural Clinical Services and Teaching (now Health Education and Training Institute Rural Porfolio, New South Wales Health), Grant/Award Number: 2009/2459

Abstract

Rationale, aims, and objectives Use of continuous subcutaneous insulin infusion therapy in type 1 diabetes management is high. However, the incorporation of this technology into self-care is not without challenges, and the support of an appropriately skilled health care team is recommended. This study aimed to examine the support context for patients using continuous subcutaneous insulin infusion therapy from the health care professional perspective, as well as contextual influences for health care professionals and their patients.

Methods This ethnographic qualitative study was undertaken in New South Wales, Australia. Recruitment occurred using a snowball sampling technique, beginning with members of an established diabetes service group. Data were collected through the use of semistructured interviews undertaken by telephone and analysed using thematic analysis.

Results Data were obtained from 26 interviews with staff from diverse professional backgrounds. An overarching theme of difficulties, disconnections, and disarray emerged, with findings indicating that participants perceived difficulties in relation to shortages of health care professional continuous subcutaneous insulin infusion–related expertise, and disconnected and disarrayed service structures and process, with barriers to access to these devices. Individual health care professionals were left to manage somehow or opted not to engage with related care.

Conclusions Findings provide insights from health care professionals' perspectives into the complexity of providing support for patients using continuous subcutaneous insulin infusion therapy across diverse contexts, and provide a platform for further research and service development. The need for consistent and coordinated care, and the infrastructure to facilitate this, flags an opportunity to drive integration of care and teamworking across as well as within settings and disciplines.

KEYWORDS

delivery of health care, diabetes mellitus type 1, insulin infusion systems, patient care

[Production Note: This paper is not included in this digital copy due to copyright restrictions.]

Perry, L., James, S., Gallagher, R., Dunbabin, J., Steinbeck, K. & Lowe, J. 2017, 'Supporting patients with type 1 diabetes using continuous subcutaneous insulin infusion therapy: Difficulties, disconnections, and disarray', *Journal of Evaluation in Clinical Practice*, 23(4):719–724. doi:10.1111/jep.12703

Appendix 10: Interview schedule

Thinking about the young people with type 1 diabetes on your caseload who use an insulin pump, now or in the recent past:

1. Have any of your patients ever used an insulin pump? How many would you have, and can you tell me a little about them, including where they were started on their pump or who initiated their insulin pump treatment?
2. What is your role in their ongoing care? For example, are you actively involved in supporting and monitoring their pump use? If so, please describe.
3. Within your area, how many healthcare professionals are actively involved with initiating, monitoring and supporting young people with insulin pumps? What are their roles?
4. Are there sufficient services and knowledgeable health care professionals available to treat young adults with pumps in your area?

   If not, which areas are well serviced and which could be strengthened?
5. Have there been any recent changes to improve services in your area? If so, please describe them.

   What sort of differences are they making? (to service provision and to the cost of service provision)
6. What are the enablers and barriers to interactions with other service providers (GPs, physicians, hospital staff, private providers like dietitians, podiatrists, optometrists, ophthalmologists, pathology) in better managing young people using insulin pumps?

   Can you suggest anything that might improve this?
7. What are your thoughts about the adequacy of current service models and

processes for initiation, maintenance and support of young people on insulin pumps to meet future demand in your diabetes service?

8. Is there anything else you would like to add?

Appendix 11: Published paper

Original Article

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Diabetes Educators' Intended and Reported Use of Common Diabetes-Related Technologies: Discrepancies and Dissonance

Steven James, RN, CDE[1], Lin Perry, PhD, MSc, RN[1], Robyn Gallagher, PhD, MN, RN[2], and Julia Lowe, MBChB, MRCP, FRCP, MMedSci[3]

Abstract

Background: Technology provides adjuvant and/or alternative approaches to care and may promote self-care, communication, and engagement with health care services. Common recent technologies for diabetes include continuous subcutaneous insulin infusions (insulin pumps), continuous glucose monitoring systems, smartphone and tablet applications, and telehealth (video conferencing). This study reports Australian diabetes educators' intentions and reported professional use of these technologies for people with type 1 diabetes, and factors predictive of this.

Methods: An anonymous, web-based questionnaire based on the technology acceptance model was distributed to members of the Australian Diabetes Educators Association through their electronic newsletter. Exploratory factor analysis revealed a 5-factor solution comprising confidence and competence, improving clinical practice, preparation (intentions and training), ease of use, and subjective norms. Logistic regression analyses identified factors predicting intention and use of technology.

Results: Respondents (n = 228) had high intentions to use technology. The majority reported using continuous subcutaneous insulin infusions, continuous glucose monitoring systems, and applications with patients, but usage was occasional. Confidence and competence independently predicted both intentions and use of all 4 technologies. Preparation (intentions and training) independently predicted use of each technology also.

Conclusions: Discrepancies and dissonance appear between diabetes educators' intentions and behavior (intentions to use and reported technology use). Intentions were higher than current use, which was relatively low and not likely to provide significant support to people with type 1 diabetes for disease management, communication, and engagement with health care services. Continuing education and experiential learning may be key in supporting diabetes educators to align their intentions with their practice.

Keywords

applications, continuous glucose monitoring system, continuous subcutaneous insulin infusion, diabetes educators, technology acceptance model, telehealth

Globally, type 1 diabetes (T1D) incidence is increasing, which is challenging many health systems. Overall incidence is increasing by around 3% each year,[1] estimated in Australia at 11 cases per 100 000 population.[2] Numbers are rising particularly in the 0-14 years age group,[3,4] a concern because onset at a young age means early potential health impact and consequent high disease burden.[5-7]

Decreasing the impact of T1D on health requires optimizing glycemic control,[8] which is not widely achieved. Better glycemic control is seen in young adults who maintain rather than lack regular contact with routine preventive care services.[9] However, many adult diabetes services are focused on older people with type 2 diabetes,[10,11] and those with T1D may struggle to access disease or age specific care; many young adults become disengaged from diabetes services.[12-14] This results in reduced diabetes self-management and well-being, and inadequate complication screening.[6,7] Innovative health care approaches are needed for young people with

[1]University of Technology Sydney, Ultimo, NSW, Australia
[2]University of Sydney, NSW, Australia
[3]Sunnybrook Health Sciences Centre, Toronto, ON, Canada

Corresponding Author:
Steven James, RN, CDE, University of Technology Sydney,15 Broadway, Ultimo, NSW, 2007, Australia.
Email: stevenjames_76@yahoo.co.uk

T1D to support their disease management and maintain and improve communication and engagement with health care services.

Technology provides potential alternative and/or adjuvant opportunities. Current common diabetes technologies include continuous subcutaneous insulin infusion (CSII) therapy, continuous glucose monitoring (CGM) systems, applications, and video conferencing (VC). Compared to injections, CSII may achieve better clinical outcomes, including reduced mortality and improved quality of life, due to increased meal-time and carbohydrate flexibility and greater convenience and discretion of insulin delivery.[15-19] Unsurprisingly, CSII use is increasing. In Australia, commencement rates have consistently increased by an average of 107 to 140 new users each month from 2004-2010. By 2011 around 10% of the T1D population were using this technology and one-third of users were aged under 20 years.[20] With glycemic control and insulin dosages reliant on blood glucose monitoring, this technology is often used in combination with CGM. More often used sporadically than continuously due to its cost,[21] CGM overcomes limitations of intermittent monitoring and has been associated with reduction in HbA1c without increased hypoglycemia risk.[19,22]

Specialized program applications ("apps") downloaded on smart phones and tablets are used to transfer blood glucose measurements electronically to health care providers.[23] They also provide timely information on, for example, carbohydrate content of foods to support self-care,[23-25] and with an estimated 74% of younger adults using smartphones,[26] this may achieve significant impact. VC is another form of internet based communication, allowing simultaneous audio and visual communication between 2 or more locations. Personal communication software such as Skype™ and FaceTime® can be used as well as commercial systems managed by health care organizations. VC can be used for continuing education as well as clinical care, and has been the means through which young people with T1D have reengaged with specialist diabetes services.[27]

However, technology use requires specialist expertise. Diabetes educators (DEs), health care professionals from disciplines such as nursing and dietetics, are key to the treatment and support of people with T1D and ideally placed to promote and support appropriate technology use. Few studies have examined health care professionals' use of diabetes-related technologies for patients with T1D.[28]

This study aimed to determine DEs' intended and reported professional use of common diabetes-related technologies for patients with T1D, and predictive factors.

The main theoretical framework underpinning the study was the technology acceptance model (TAM), an information systems theory that models how users come to accept and use a technology.[29-33] Originally developed to examine responses to computer technology, the model has been revised for translation to the health care context and used to examine, first, telemedicine technology acceptance by physicians[34] and then evaluation of home telemonitoring for patients with heart failure and/or chronic obstructive pulmonary disease.[35] Factors were added from relevant theories, mapping influences on behavioral intention from individual, technological, and organizational contexts, structured as 7 theoretical constructs.

Methods

Design and data collection

A survey design was used, and data were collected with an anonymous, web-based questionnaire. The most recent TAM model used in health care included habit, facilitating conditions, and subjective norms and omitted peer influence and perceived technology control (ability or competence).[35] No rationale was supplied for these omissions, yet perceived technology control may be important as shortages of health care professional expertise have been cited as a reason why health care professionals do not engage with CSII-related care. This 33-item version of the questionnaire[35] had 4 questions on attitude (perceived positive or negative consequences of adopting the technology) and compatibility (the degree of correspondence between a new technology and existing values, past experiences and needs of potential adopters) in the individual context. Within the technological context, 6 questions sought perceived ease-of-use and usefulness, and 3 focused on habit (behavior that has become automatic). Within the organizational context 4 questions related to subjective norms (the extent to which an individual believes that people who are important to them will approve of their behavior adoption), and 3 to facilitating conditions (the degree to which individuals believe that organizational and technical infrastructures support usage). Three questions on intention were included. Responses were measured on a 7-point Likert-type scale from –3 = totally disagree to 3 = totally agree, with scores summed for each of the 8 factors. Validity was supported by a panel of experts in technology, and Cronbach's alpha values greater than or equal to .7 were reported for all but 1 factor (habit = .56). This version of the model had never been formally tested.

Modifications to the questionnaire for this study included wording changes to relate to T1D, and removal of negative values from the Likert-type scale for more intuitive scaling (from 1 = strongly disagree to 7 = strongly agree). Seven questions were added: 1 question determined technology use and frequency measured on a 5-point Likert-type scale (1 = never, 2 = daily, 3 = weekly, 4 = monthly, and 5 = occasionally); 6 questions related to competence in provision of information and advice, data interpretation, operation, problem solving, and overall competence for these technologies (measured using the original scale of 1 = strongly disagree to 7 = strongly agree). Finally, an extra response choice of "already know," "already use," or "intend to continue" was

added to 6 questions, to distinguish existing knowledge and technology usage. The questionnaire was formatted to ask participants to consider the 4 technologies separately, and data were collected to characterize participants' age, sex, health care qualifications, and experience. The modified questionnaire was reviewed for face and content validity by 2 subject matter experts, both physicians with extensive research and diabetes experience, and piloted by 8 Canadian-based DEs; minor changes were made for ease of moving through the survey.

Exploratory factor analyses using an iterated principal axis analysis with promax rotation examined the factor structure for each of the 4 technologies separately. Discriminant validity was evaluated by inspecting the construct loadings of each factor, applying criteria of a primary factor loading of 0.4 or above and no cross-loading of 0.6 or more.[36] Initial factor analyses identified that 9 questions did not consistently load on identified factors for 3 or more of the technologies. Their exclusion resulted in a replicating 5-factor solution and improved fit across the 4 technologies. These 5 factors were confidence and competence, improving clinical practice, preparation (intentions and training), ease of use, and subjective norms. These factors explained 71.17% of the variance for the questions related to CSII, 70.13% for CGM, 71.09% for apps, and 67.95% for VC. The Kaiser-Meyer-Olkin measure of sampling adequacy was .934 or above; Bartlett's tests of sphericity were significant (CSII: $\chi^2 = 6798$, $P < .001$; CGM: $\chi^2 = 6485$, $P < .001$; apps: $\chi^2 = 6500$, $P < .001$; and VC: $\chi^2 = 5813$, $P < .001$); the diagonals of the anti-image correlation matrix were all 0.860 or above; and, excluding 1 question relating to CSII, CGM, and apps, communalities were all 0.4 or above. Finally, Cronbach's alpha values were acceptable for all factors for all technologies; for the confidence and competence factor, values ranged from .950 to .974; for improving clinical practice, from .914 to .935; and the other domains ranged from .756 to .927. Items pertaining to competence in the confidence and competence factor were highly correlated (CSII = .614-.953; CGM = .646-.944; apps = .662-.929; and VC = .481-.915); however, the explanatory power of the factor was not improved by removal of any combination of these items (Table 1).

Sample

A convenience sample was collected from members of the Australian Diabetes Educators Association (ADEA), the leading Australian organization for multidisciplinary health care professionals who provide diabetes education and care. This organization had 1747 members on June 30, 2013.[37] To be eligible, participants were required to have experience as a DE in Australia, current membership with the ADEA, and be registered to receive the ADEA's electronic newsletter; numbers of eligible members were not known. Approval for the study was obtained from the University of Technology Sydney Human Research Ethics Committee.

Procedure

The web based survey was undertaken June-August 2014. Potential participants were advised of the study and could access it through a link in the ADEA weekly electronic newsletter, operational for 12 weeks to allow for response patterns previously experienced in this population.[38] Reminders were posted in the newsletter at 2, 4, 6, 8, and 10 weeks following the first advice of the survey. Through the use of the skip logic feature in SurveyMonkey®, respondents were only asked relevant questions based on their previous responses. A total of 247 questionnaires were partially or fully completed; 19 provided only demographic data and were omitted from data analyses.

Data analyses

Data were entered into SPSS© version 23 software. Area of employment was categorised,[39] and for each of the 4 technologies, responses for reported technology use were categorized (no/yes) and compared with socio-demographic data using the chi-square test, where theoretical or clinical reasons identified these characteristics as potential influences.[40,41] Questions were otherwise analyzed as ordinal measures and summed for each of the 5 factors, and for the 3 questions relating to intentions; 2 questions required reverse coding. Frequencies and medians (25, 75 quartile) scores, where appropriate, were used descriptively.

Logistic regression analyses were undertaken to identify independent predictors of DEs' intentions and reported use of the 4 technologies. Dependent variables were intention to use each technology summary scores dichotomized at median scores into low and high intention (due to nonnormal distribution), and reported use (no/yes). Potential predictor variables comprised summary scores of the 5 factors identified through the factor analyses (though the single-item factor preparation [intentions and training] was not considered for analyses as a potential predictor of technology intention) and sociodemographic data. The backward entry method was selected to create the most parsimonious model and adjusted odds ratios and 95% confidence intervals reported. All assumptions of the models were tested and met. A P value < .05 was considered significant.

Results

The majority of respondents (n = 228) were female nurses, although multiple disciplines were represented (Table 2). Respondents had many years of experience in both their professions and in diabetes education, and were well educated. Most were presently credentialed with the ADEA and had experience working with pediatric and/or young adult patients with T1D; of those with experience working with pediatric patients with T1D, almost all (n = 125, 99.2%) also had experience with young adults with T1D. Most (91.7%)

Table 1. Factor Structure.

Factor	Question	Original factor
Confidence and competence	Use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) would necessitate major changes in my clinical practice:	Compatibility
	I feel comfortable with the following diabetes-related technologies:	Habit
	I already use the following diabetes-related technologies (where suitable) in the management of patients with type 1 diabetes:	Habit
	I often use the following diabetes-related technologies in my work:	Habit
	I am competent overall with the following diabetes-related technologies:	
	I am competent providing information about the following diabetes-related technologies:	
	I am competent interpreting data obtained from the following diabetes-related technologies:	
	I am competent providing advice to patients about the following diabetes-related technologies:	
	I am competent operating the following diabetes-related technologies:	
	I am competent problem-solving with the following diabetes-related technologies:	
Improving clinical practice	I think it is a good idea to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable):	Attitude
	Use of the following diabetes-related technologies may be/are beneficial for the care of my patients with type 1 diabetes (where suitable):	Attitude
	In my opinion, use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) will have/has a positive impact:	Attitude
	Use of the following diabetes-related technologies may promote good clinical practice:	Compatibility
	Use of the following diabetes-related technologies (where suitable) may improve management of my patients with type 1 diabetes:	Usefulness
	The following diabetes-related technologies can improve my performance in care of my patients with type 1 diabetes (where suitable):	Usefulness
	The following diabetes-related technologies can facilitate the care of my patients with type 1 diabetes (where suitable):	Usefulness
	In general, the following diabetes-related technologies may be useful/are useful to improve the care of my patients with type 1 diabetes (where suitable):	Usefulness
Preparation (intentions and training)	I would use the following diabetes-related technologies if I receive appropriate training:	Facilitating conditions
	I would use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) if I receive the necessary technical assistance:	Facilitating conditions
	I intend to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) when they are available at my centre:	Intention
	I intend to use the following diabetes-related technologies when necessary to provide health care to my patients with type 1 diabetes:	Intention
	I intend to use the following diabetes-related technologies routinely for the care of my patients with type 1 diabetes (where suitable):	Intention
Ease of use	I think it would be/is easy to perform the tasks necessary to manage my patients with type 1 diabetes using the following diabetes-related technologies (where suitable):	Ease of use
	I believe that the following diabetes-related technologies will be/are clear and easy to understand:	Ease of use
	I think I will find it easy/I found it easy to acquire the skills necessary to use the following diabetes-related technologies:	Ease of use
	I think that the following diabetes-related technologies will be/are easy to use:	Ease of use
Subjective norms	Most of my patients with type 1 diabetes welcome/would welcome me using the following diabetes-related technologies:	Subjective norms
	Health Managers would welcome/welcome me using the following diabetes-related technologies:	Subjective norms
	Other health professionals (nurses, other specialist, etc) would welcome/welcome me using the following diabetes-related technologies:	Subjective norms

were currently working in Australia and in cities, with all states and territories of Australia represented.

Summary scores of the 5 factors identified from the questionnaire as potentially influential for technology adoption were relatively consistent across the 4 technologies (Figure 1). Highest scores indicated that respondents strongly perceived positive consequences for patient care of adopting the 4 technologies; the lowest scores were for respondents' reported confidence and competence. With maximum possible scores of 7 (1 = strongly disagree to 7 = strongly agree), overall respondents reported they felt competent with CSII (median [25, 75 quartile] score 6 [3, 7]), and somewhat

Table 2. Respondent Characteristics.

Characteristic (n = 228 unless noted)	n (%) (unless noted)
Age (years), mean (SD, min-max)	47 (10, 24-66)
Experience (years), median (25, 75 [min-max])	
In their profession	20 (10.5, 30 [1-48])
In diabetes education	8 (4, 14 [1-40])
Male gender	26 (11.4)
Profession	
Nurse	209 (91.7)
Dietitian	16 (7)
Other	3 (1.3)
Highest professional qualification	
Master's	43 (18.9)
Diploma	66 (28.9)
Bachelor's ± honors degree	119 (52.2)
Presently credentialed with the ADEA (yes)	167 (73.2)
Young adult experience[a] (yes)	209 (95.4)
Pediatric experience[a] (yes)	126 (57.5)
Area of employment (n = 203)	
Major city	141 (69.5)
Inner regional	42 (20.7)
Outer regional	15 (7.4)
Rural and remote	5 (2.5)

[a]Working with respective patients with type 1 diabetes.

competent with CGM (5 [3, 7]) and apps (5 [3, 6]). However, they neither agreed nor disagreed they were competent with VC (4 [2, 5]). They reported at least some degree of competence with each facet identified (Figure 2).

Respondents had strongly positive intentions to use common diabetes-related technologies for patients with T1D, particularly CSII and CGM; somewhat less so for apps and VC (Figure 3). The majority of respondents also reported using CSII, CGM and apps for patients with T1D. Around 4 of every 5 respondents reported using CSII (80.3%), around 2 in 3 used CGM (65.4%) or apps (69.7%), but only around 1 in 3 used VC (36.4%). Significantly greater proportions of those with, rather than lacking, experience working with pediatric patients with T1D reported using CGM, apps, or VC. A greater proportion of DEs employed outside of major cities reported using VC. Overall, where these technologies were used; this was on an "occasional" basis.

Many predictors of both intended and reported actual use of common diabetes-related technologies exhibited substantial effects across the technologies. Confidence and competence consistently positively predicted DEs' intentions to use each of the 4 technologies; ease of use was also predictive of intention to use apps and VC; years worked in diabetes education positively predicted intention to use apps (Figure 4a; Table 3). Subjective norms were also important, positively predicting DEs' intentions to use VC; perceived improvement to clinical practice consistently and positively predicted DEs' intention to use all technology except VC. Employment in a major city was predictive of DEs' intentions to use apps.

Predictive factors were shown to relate both positively and negatively to reported technology use (Figure 4b; Table 4). As for intention to use, DEs' confidence and competence consistently positively predicted actual usage of all 4 technologies, as did preparation (intentions and training). Years worked in diabetes education positively predicted DEs' reported use of both CGM and apps; experience working with pediatric patients with T1D positively predicted CGM use. However, lack of ease of use was a negative predictor, or deterrent, of CSII and CGM usage. Subjective norms were again of importance, negatively predictive of use of apps, with perceived negative effects for clinical practice linked to lower use of VC.

Discussion

Our research indicates discrepancies and dissonance between DEs' strongly positive intentions to use common diabetes-related technology for patients with T1D and their reported actual usage, which is occasional and not likely to be adequate to support effective disease management or patients' communication and engagement with health care services. It also highlights key factors that can be targeted to address this gap.

To increase technology adoption, DEs' confidence and competence, their preparation (intentions and training), and their perceptions of the ease of use of the technologies are all important. Education has been widely reported as crucial to support change in these areas,[42-46] and may be targeted to help address these predictive factors. With technology use in T1D management increasing this should feature as part of routine continuing professional development for those who care for people with diabetes. The form in which this is delivered is likely to influence its uptake and effectiveness. The principles of adult learning[47] mesh with these findings to suggest such education should support DEs as autonomous and self-directed learners, should be goal and relevancy focused, and contain elements of experiential learning. There is potential for the ADEA to expand their role by initiating, promoting and/or developing and making available relevant educational programs.

Other influences were subjective norms and technologies' perceived contribution to improving clinical practice; both could be addressed locally through, for example, experiential evidence- based workshops led by respected opinion leaders. Broadening DEs' clinical experience by rotating local placements might also be helpful. Young adults' experiences of pediatric diabetes care have been reported as significant influences on their expectations of care as they transition to adult-based diabetes care, with unmet expectations linked to care disengagement.[48-50] Clinical placements across pediatric and

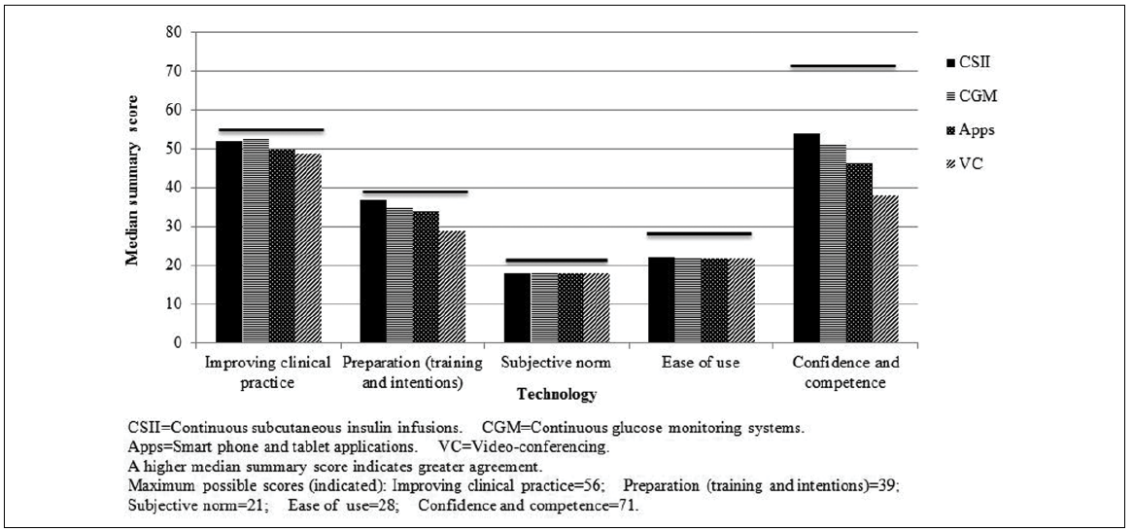

Figure 1. Factors Influencing Diabetes Educators' Reported Use of Common Diabetes-Related Technologies for Patients with Type 1 Diabetes.

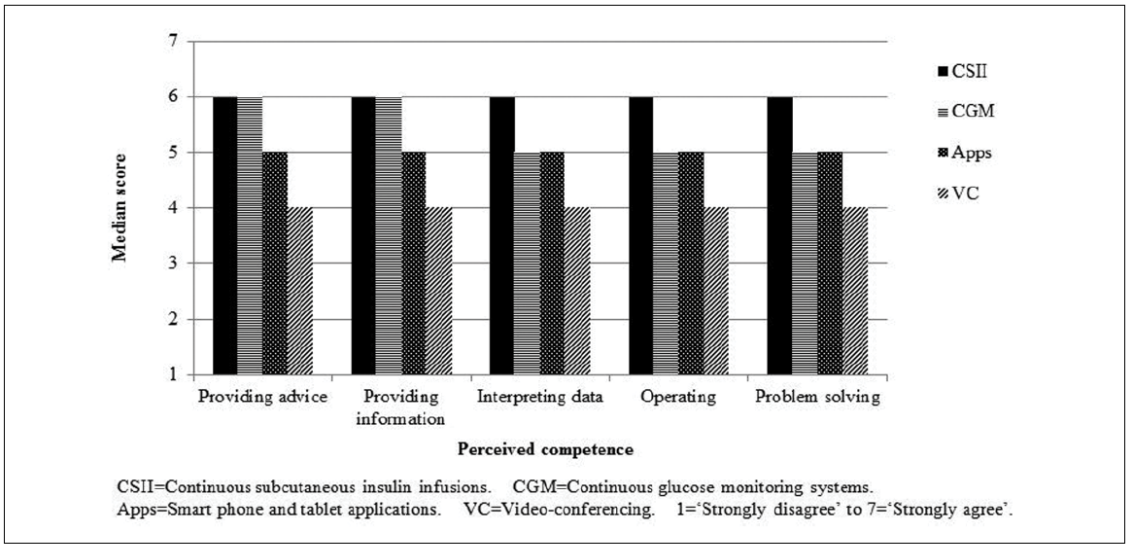

Figure 2. Diabetes Educators' Reported Competence in Use of Common Diabetes-Related Technologies for Patients with Type 1 Diabetes.

adult diabetes care settings may be one means to increase DEs' exposure to a range of care models as well as technologies, and better align the norms of practice in different settings for greater consistency of experience for young people.

Findings relating to VC were notably different to those of these other technologies. This was not surprising because this technology is used for rather different purposes; a means of conversing with patients rather than routine day to day clinical care. There are obvious differences in need for this technology, and hence exposure, for those in cities compared to regional and rural areas. However, participants may also have interpreted these questions differently. Some may have responded based on experiences with VC in the form of personal communication software such as Skype and FaceTime, whereas

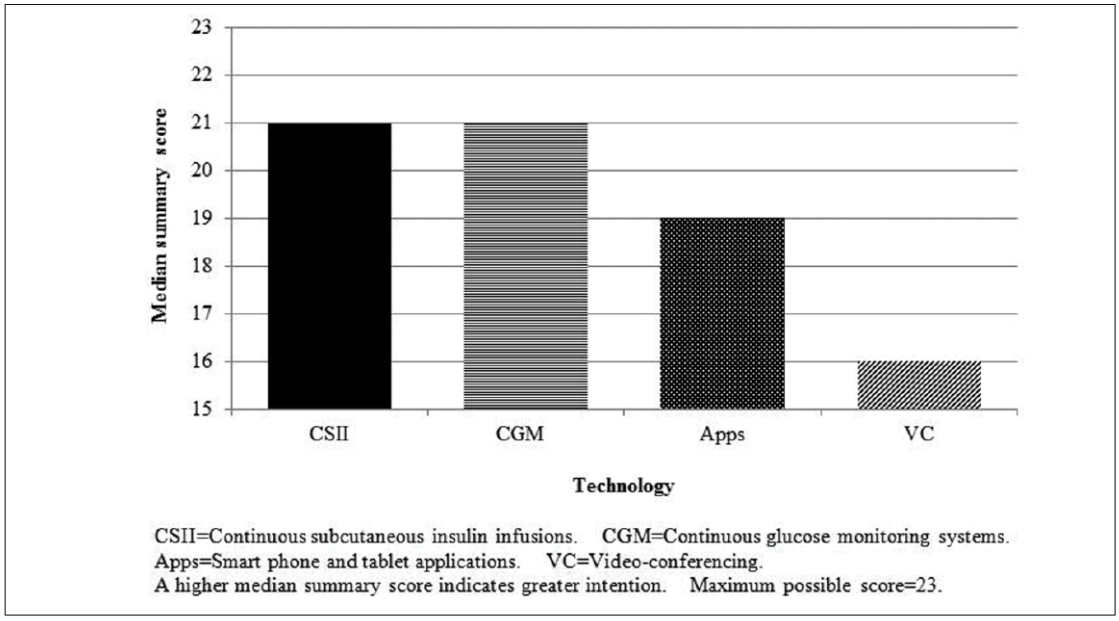

Figure 3. Diabetes Educators' Intentions to Use of Common Diabetes-Related Technologies for Patients with Type 1 Diabetes.

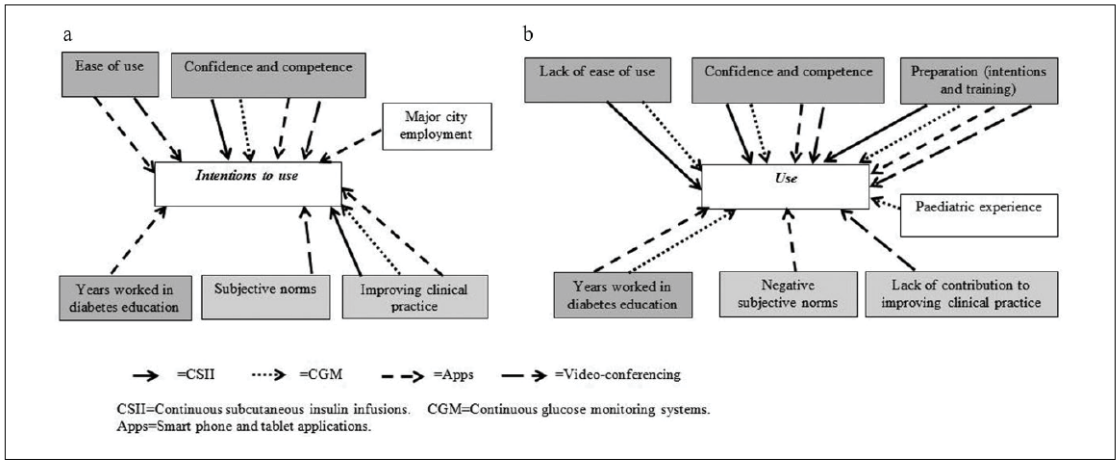

Figure 4. Common Diabetes-Related Technologies-Influences on Diabetes Educators' Intentions and Reported Use.

others may have been thinking of commercial systems managed by health care organizations; these differing systems, contexts, security concerns and technology performance may have influenced DEs' reported attitudes and intentions. For the future, personal use of these and other diabetes-related technologies should be investigated, and how this may influence professional attitudes and behaviors, and other barriers and supports to technology use in a clinical setting.

Study limitations include the potential for responder bias and use of self-report data, intrinsic to survey design. Use of an online survey may have also preselected technology-oriented clinicians. Strengths derive from the history and rigor of the development of the model and the ensuing questionnaire instrument. Recruitment was successful across a wide and diverse geographical and sociological area, and may well have achieved a sample representative of eligible ADEA membership.

Table 3. Independent Predictors of Diabetes Educators' Intentions to Use Common Diabetes-Related Technologies for Patients With Type 1 Diabetes.

Dependent	CSII		CGM		Apps		Video conferencing	
Independent	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Confidence and competence	1.12 (1.08-1.16)	<.001	1.11 (1.07-1.15)	<.001	1.07 (1.03-1.1)	<.001	1.05 (1.02-1.09)	.002
Improving clinical practice	1.15 (1.05-1.26)	.003	1.33 (1.18-1.5)	<.001	1.17 (1.077-1.28)	<.001		
Ease of use					1.15 (1.07-1.31)	.027	1.21 (1.08-1.35)	.001
Subjective norms	1.15 (0.98-1.34)	.085					1.21 (1.07-1.37)	.003
Age (in years)	0.95 (0.89-1.01)	.095						
Years worked in diabetes education					1.09 (1.01-1.18)	.034		
Pediatric experience[a] (no/yes)							2.05 (0.88-4.77)	.096
Employment major city (no/yes)					2.87 (1.04-7.0)	.041		
Constant: *B* (*SE*)	−12.00 (3.25)		−19.25 (3.49)		−15.68 (2.63)		−8.97 (1.49)	
Omnibus test of model coefficient: χ^2	134.94		131.18		115.79		88.96	

Backward logistic regression.
[a]Working with respective patients with type 1 diabetes.

Table 4. Independent Predictors of Diabetes Educators' Reported Use of Common Diabetes-Related Technologies for Patients With Type 1 Diabetes.

Dependent	CSII		CGM		Apps		Video conferencing	
Independent	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Confidence and competence	1.14 (1.07-1.2)	<.001	1.17 (1.1-1.25)	<.001	1.12 (1.07-1.18)	<.001	1.12 (1.07-1.17)	<.001
Improving clinical practice							0.92 (0.85-0.99)	.019
Preparation (intentions and training)	1.23 (1.07-1.43)	.005	1.16 (1.01-1.33)	.031	1.26 (1.11-1.42)	<.001	1.15 (1.02-1.31)	.025
Ease of use	0.75 (0.63-0.9)	.002	0.72 (0.58-0.9)	.003	0.89 (0.79-1.02)	.086	0.87 (0.75-1.0)	.053
Subjective norms	0.84 (0.67-1.04)	.103			0.76 (0.65-0.89)	<.001		
Age (in years)	1.06 (1.0-1.13)	.061						
Years worked in diabetes education			1.28 (1.1-1.49)	.001	1.12 (1.02-1.22)	.022		
Presently ADEA credentialed (no/yes)			0.24 (0.05-1.23)	.087				
Pediatric experience[a] (no/yes)			5.10 (1.41-18.42)	.013				
Employment major city (no/yes)							2.25 (0.89-5.69)	.085
Constant: *B* (*SE*)	−3.59 (2.74)				−4.41 (1.59)		−2.94 (1.43)	
Omnibus test of model coefficient: χ^2	71.96		133.46		99.77		95.13	

Backward logistic regression.
[a]Working with respective patients with type 1 diabetes.

Conclusions

This research is important because it explores previously little-examined attitudes and behaviors of an essential professional group supporting people with T1D. Findings indicate discrepancies and dissonance between DEs' strongly positive intentions toward use of common diabetes-related technology for patients with T1D and their reported actual usage, which is only occasional and probably inadequate for patient support. Continuing education using the principles of adult learning may be key in supporting DEs to align their intentions with their practice. Embedding engagement with technologies within DE practice may help maintain and improve patients' communication and engagement with diabetes services and with this their self-management of their diabetes. While this may necessitate some resource reconfiguration, findings suggest how this may be approached to maximize realization of the potential benefits of these new but now common diabetes technologies.

Abbreviations

ADEA, Australian Diabetes Educators Association; App, application; CGM, continuous glucose monitoring; CI, confidence interval; CSII, continuous subcutaneous insulin infusion; DE, diabetes educator; OR, odds ratio; TAM, technology acceptance model; T1D, type 1 diabetes; VC, video conferencing.

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Wang (clinical epidemiologist and statistician), University of Technology Sydney.

Declaration of Conflicting Interests

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Appendix 12: Web-based survey

The purpose of this questionnaire is to determine the views and self-reported competence of Diabetes Educators in Australia in use of the following diabetes-related technologies in patients with type 1 diabetes:

- Insulin pumps;
- Continuous glucose monitoring systems;
- Mobile phone and tablet applications; and
- Video-conferencing.

Some of the questions are deliberately similar as they relate to different aspects of the same issue. Please tell me a little about yourself then read the statements and rate each one using the scale provided for each of the four diabetes-related technologies. Some questions may not be applicable to you: if so, please check the 'Already use' or like statement box. A progress bar at the bottom of each page will highlight how far you are into the survey and your answers will be automatically saved as you complete each page.

1. **'Have you ever (including in your present position) practiced as a Diabetes Educator in Australia?'**

   Yes ☐ No ☐

2. **'What is your age (in years)?'** _____

2. **'What is your gender?'**

   Male ☐ Female ☐

3. **'What is your current profession?'**

   Registered Nurse ☐ Accredited Practising Dietician ☐

   Registered Medical Practitioner (Doctor) ☐ Registered Pharmacist ☐

   Registered Podiatrist ☐ Accredited Exercise Physiologist ☐

   Other (please indicate) _____

4. **'How many years have you worked in your current profession?'** _____

5. **'What is your highest professional-related academic qualification?'**

   Diploma ☐ Degree (not Honours) ☐

   Honours Degree ☐

   Masters ☐ PhD ☐

   Other (please indicate) _____

6. 'Have you obtained any (other) diabetes-specific qualification(s)?'

Yes ☐ Please detail: _____

No ☐

7. 'How many years have you worked as a Diabetes Educator?' _____

8. 'Are you presently a Credentialled Diabetes Educator with the Australian Diabetes Educators Association?'

Yes ☐ No ☐

9. 'Have you any experience working as a Diabetes Educator with patients with type 1 diabetes?'

Yes ☐ No ☐

10. 'As a Diabetes Educator have you ever (including in previous positions) cared for paediatric patients with type 1 diabetes?'

Yes ☐ No ☐

11. 'As a Diabetes Educator have you ever (including in previous positions) cared for young adults (aged 18 - 30 years) with type 1 diabetes?'

Yes ☐ No ☐

12. 'Are you currently working as a Diabetes Educator?'

Yes ☐ No ☐

13. 'Are you currently employed overseas?'

Yes ☐ No ☐

14. 'In what town or city are your currently employed?' _____

15. 'In what State or Territory are you currently employed?'

Victoria	☐	New South Wales	☐
Queensland	☐	South Australia	☐
Northern Territory	☐	Western Australia	☐
Tasmania	☐	The Australian Capital Territory	☐

16. 'Are you currently employed within the Hunter New England Local Health District/Hunter New England Health?'

Yes ☐ No ☐

Next there are some statements expressing the frequency of, and views and self-reported competence towards use of diabetes-related technologies (by this we mean insulin pumps, continuous glucose monitoring systems and telehealth via mobile phone and tablet applications, and video-conferencing). Please indicate your level of agreement.

Never ***Daily*** ***Weekly*** ***Monthly*** ***Occasionally***

17. I work with the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable):

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

Strongly disagree ***neither agree nor disagree*** ***Strongly agree***

1 ***2*** ***3*** ***4*** ***5*** ***6*** ***7***

18. I feel comfortable with the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

19. The use of the following diabetes-related technologies could help/helps me to manage my patients with type 1 diabetes (where suitable) more rapidly:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

20. I think that I could easily learn how to use the following diabetes-related technologies:

Insulin pumps	[ ]	OR Already know	[ ]
Continuous glucose monitoring systems	[ ]	OR Already know	[ ]
Mobile phone and tablet applications	[ ]	OR Already know	[ ]
Video-conferencing	[ ]	OR Already know	[ ]

21. I think it is a good idea to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable):

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

22. I intend to use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) when they are available at my centre:

Insulin pumps	[ ]	OR Already use	[ ]
Continuous glucose monitoring systems	[ ]	OR Already use	[ ]
Mobile phone and tablet applications	[ ]	OR Already use	[ ]
Video-conferencing	[ ]	OR Already use	[ ]

23. **Use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) would necessitate major changes in my clinical practice:**

Insulin pumps	[ ]	OR Already use	[ ]
Continuous glucose monitoring systems	[ ]	OR Already use	[ ]
Mobile phone and tablet applications	[ ]	OR Already use	[ ]
Video-conferencing	[ ]	OR Already use	[ ]

24. **Use of the following diabetes-related technologies (where suitable) may improve management of my patients with type 1 diabetes:**

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

25. **I think it would be/is easy to perform the tasks necessary to manage my patients with type 1 diabetes using the following diabetes-related technologies (where suitable):**

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

26. **Most of my patients with type 1 diabetes welcome/would welcome me using the following diabetes-related technologies:**

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

27. **I think that my centre has the necessary infrastructure to support my use of the following diabetes-related technologies (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

28. **The following diabetes-related technologies could (where suitable) help me get the most out of my time to manage my patients with type 1 diabetes:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

29. **I believe that the following diabetes-related technologies will be/are clear and easy to understand:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

30. **Use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) are compatible with my work habits:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

31. **Most of my colleagues would welcome/welcome me using the following diabetes-related technologies in the care of patients with type 1 diabetes (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

32. **The following diabetes-related technologies can improve my performance in care of my patients with type 1 diabetes (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

33. **I think the following diabetes-related technologies are flexible for different contexts or circumstances:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

34. **I would/do find it interesting to use the following diabetes-related technologies for the management of my patients with type 1 diabetes (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

35. I intend to use the following diabetes-related technologies when necessary to provide healthcare to my patients with type 1 diabetes:

Insulin pumps	[ ]	OR Intend to continue	[ ]
Continuous glucose monitoring systems	[ ]	OR Intend to continue	[ ]
Mobile phone and tablet applications	[ ]	OR Intend to continue	[ ]
Video-conferencing	[ ]	OR Intend to continue	[ ]

36. I already use the following diabetes-related technologies (where suitable) in the management of patients with type 1 diabetes:

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

37. Health Managers would welcome/welcome me using the following diabetes-related technologies:

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

38. The following diabetes-related technologies can facilitate the care of my patients with type 1 diabetes (where suitable):

Insulin pumps	[ ]	Continuous glucose monitoring systems	[ ]
Mobile phone and tablet applications	[ ]	Video-conferencing	[ ]

39. Use of the following diabetes-related technologies may promote good clinical practice:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

40. Use of the following diabetes-related technologies may be/are beneficial for the care of my patients with type 1 diabetes (where suitable):

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

41. I think I will find it easy/I found it easy to acquire the skills necessary to use the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

42. I would use the following diabetes-related technologies if I receive appropriate training:

Insulin pumps [ ] OR Already use [ ]

Continuous glucose monitoring systems [ ] OR Already use [ ]

Mobile phone and tablet applications [ ] OR Already use [ ]

Video-conferencing [ ] OR Already use [ ]

43. **Other health professionals (nurses, other specialist etc.) would welcome/welcome me using the following diabetes-related technologies:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

44. **In general, the following diabetes-related technologies may be useful/are useful to improve the care of my patients with type 1 diabetes (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

45. **I intend to use the following diabetes-related technologies routinely for the care of my patients with type 1 diabetes (where suitable):**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

46. **Use of the following diabetes-related technologies may interfere/interferes with the follow-up of my patients with type 1 diabetes:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

47. **I think that the following diabetes-related technologies will be/are easy to use:**

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

48. In my opinion, use of the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) will have/has a positive impact:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

49. I would use the following diabetes-related technologies in the care of my patients with type 1 diabetes (where suitable) if I receive the necessary technical assistance:

Insulin pumps [ ] OR Already use [ ]

Continuous glucose monitoring systems [ ] OR Already use [ ]

Mobile phone and tablet applications [ ] OR Already use [ ]

Video-conferencing [ ] OR Already use [ ]

50. I often use the following diabetes-related technologies in my work:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

51. I am competent overall with the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

52. I am competent providing information about the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

53. I am competent interpreting data obtained from the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

54. I am competent providing advice to patients about the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

55. I am competent operating the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

56. I am competent problem-solving with the following diabetes-related technologies:

Insulin pumps [ ] Continuous glucose monitoring systems [ ]

Mobile phone and tablet applications [ ] Video-conferencing [ ]

57. What do you think the Australian Diabetes Educators Association could do to improve knowledge, competence and/or confidence of diabetes-related technologies (insulin pumps, continuous glucose monitoring systems and telehealth via mobile phone and tablet applications, and video-conferencing) amongst Diabetes Educators?

_____

_____

_____

58. What other suggestions do you have on how to improve knowledge, competence or confidence of diabetes related technologies (insulin pumps, continuous glucose monitoring systems, and telehealth via mobile phone and tablet applications, and video-conferencing) amongst Diabetes Educators?

_____

_____

_____

Appendix 13: Human research ethics approval

Outlook

Type here to search | Entire Mailbox | Privacy | Options | Sign out

Mail

Reply | Reply All | Forward | Junk | Close

Deleted Items (128)
Drafts [122]
Inbox
Junk E-Mail
Sent Items

Click to view all folders

Clutter
Old e-mails ADC
Transferred from yahoo a...
Transferred from yahoo a...
Transferred from yahoo a...

Manage Folders...

UTS HREC Approval
Research.Ethics@uts.edu.au [Research.Ethics@uts.edu.au]
You forwarded this message on 6/06/2014 12:53 AM.
Sent: Wednesday, 4 June 2014 4:04 PM
To: Steven James; Lin.Perry@uts.edu.au; Research.Ethics@uts.edu.au

Dear Applicant

The UTS Human Research Ethics Committee reviewed your application titled, "Australian Diabetes Educators' use of diabetes-related technologies", and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct in Human Research (2007). I am pleased to inform you that ethics approval is now granted.

Your approval number is UTS HREC REF NO. 2014000287
Your approval is valid five years from the date of this email.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually from the date of approval, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network:
http://rmprod.itd.uts.edu.au/RMENet/HOM001N.aspx
* if accessing outside of UTS network:
https://remote.uts.edu.au , and click on "RMENet - ResearchMaster Enterprise" after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to:
http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Professor Marion Haas

Appendix 14: Participant information statement - web-based survey

Australian Diabetes Educators' use of diabetes-related technologies

(UTS HREC Approval Number 2014000287)

My name is Steven James and I am a student at the University of Technology, Sydney undertaking a Doctor of Philosophy (Nursing), under the supervision of Professors Lin Perry and Robyn Gallagher. I am a Registered Nurse and Credentialled Diabetes Educator, undertaking research to determine Diabetes Educators' views, experiences, self-reported competence, and perceived supports and hindrances towards the use of diabetes-related technologies in patients with type 1 diabetes (insulin pumps, continuous glucose monitoring systems and telehealth via mobile phone and tablet applications, and video-conferencing). My research is linked to a service development program being undertaken in Hunter New England, New South Wales.

As a member of the Australian Diabetes Educators Association you are likely to practice within the specialty field of diabetes care and education. If you have current or past experience as a Diabetes Educator in Australia, you are invited to participate in my research by completing an anonymous online questionnaire which takes around 15 minutes to finish. The questions ask about your views of diabetes-related technologies, and self-reported competence in their use.

As the survey is anonymous, you will not be identifiable in any information you give me. Only members of the research team will have access to survey responses and findings will be published in a form that does not identify anyone. If you have any

concerns about the research please contact me via e-mail at Steven.B.James-1@student.uts.edu.au or my supervisor at Lin.Perry@uts.edu.au. If you would like to talk to someone who is not connected with the research, contact the University of Technology, Sydney Research Ethics Officer on 02 9514 9772 or at Research.ethics@uts.edu.au and quote this number (UTS HREC approval number 2014000287).

If you agree to be part of the research, please click on the following web-link to commence answering of the survey questions: www.surveymonkey.com/s/YHWBGBP.

Appendix 15: Published paper

Original Article

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Diabetes Educators: Perceived Experiences, Supports and Barriers to Use of Common Diabetes-Related Technologies

Steven James, RN, CDE[1], Lin Perry, PhD, MSc, RN[2], Robyn Gallagher, PhD, MN, RN[3], and Julia Lowe, MBChB, FRCP, MMedSci[4]

Abstract

Background: Various technologies are commonly used to support type 1 diabetes management (continuous subcutaneous insulin infusion therapy, continuous glucose monitoring systems, smartphone and tablet applications, and video conferencing) and may foster self-care, communication, and engagement with health care services. Diabetes educators are key professional supporters of this patient group, and ideally positioned to promote and support technology use. The aim of this study was to examine diabetes educators' perceived experiences, supports, and barriers to use of common diabetes-related technologies for people with type 1 diabetes.

Methods: This qualitative ethnographic study recruited across metropolitan, regional and rural areas of Australia using purposive sampling of Australian Diabetes Educators Association members. Data were collected by semistructured telephone interviews and analyzed using thematic analysis.

Results: Participants (n = 31) overwhelmingly indicated that overall the use of technology in the care of patients with type 1 diabetes was burdensome for them. They identified 3 themes involving common diabetes-related technologies: access to technology, available support, and technological advances. Overall, these themes demonstrated that while care was usually well intentioned it was more often fragmented and inconsistent. Most often care was provided by a small number of diabetes educators who had technology expertise.

Conclusions: To realize the potential benefits of these relatively new but common diabetes technologies, many diabetes educators need to attain and retain the skills required to deliver this essential component of care. Furthermore, policy and strategy review is required, with reconfiguration of services to better support care delivery.

Keywords

applications, barriers, continuous glucose monitoring system, continuous subcutaneous insulin infusion, diabetes educators, supports, telehealth

The incidence of type 1 diabetes (T1D) is rising approximately 3% per annum internationally.[1] The substantial impact of T1D on health and disease burden has been documented, as has the importance of tight glycemic control to avoid or defer disease complications.[2,3] The majority of adult diabetes services are oriented toward the management of type 2 diabetes, the most common diabetes form;[4,5] as a consequence, people with T1D may find it hard to access disease or age-specific care.

Technology can provide innovative approaches to T1D health care.[6] Common technologies can be broadly categorized as related to insulin delivery, blood glucose monitoring, and communication, each category with multiple media. For insulin delivery, compared to injections, continuous

[1]University of Technology Sydney, Ultimo, NSW, Australia
[2]University of Technology Sydney/South East Sydney Local Health District, Prince of Wales Hospital, Randwick, NSW, Australia
[3]University of Sydney, Sydney, NSW, Australia
[4]Sunnybrook Health Sciences Centre, Toronto, ON, Canada

Corresponding Author:
Steven James, RN, CDE, University of Technology Sydney, 15 Broadway, Ultimo, NSW, 2007, Australia.
Email: stevenjames_76@yahoo.co.uk

subcutaneous insulin infusion (CSII; insulin pump) therapy has demonstrated improved quality of life, glycemic control for some, reduced mortality, and economic benefit.[7-14] With usage increasing, by 2011 in Australia approximately 10% of the T1D population were using CSII technology, with half of all users aged under 25 years.[15] Many CSII devices are obtained through a government subsidy for low income families with children with T1D, introduced in 2008 or, more commonly, private health insurance.[16]

Insulin dosage calculation is reliant on blood glucose monitoring. Continuous glucose monitoring (CGM) technology overcomes the limitations of intermittent monitoring and has been associated with HbA1c reduction without increased hypoglycemia risk, higher treatment satisfaction and improved quality of life.[6,14,17,18] Software packages currently available for both CSII therapy and CGM systems enable transfer of data to a health care professional (HCP) via the Internet.[19] However, use is limited by the requirement for personal computers, significant patient effort, and time commitment.[20]

Specialized program applications (apps) downloaded on smartphones and tablets support self-care through timely provision of information on blood glucose, diet, and exercise patterns; and this information can be shared electronically with health care providers.[19,21,22] Another communication modality is video conferencing (VC), which allows simultaneous audio and visual communication between 2 or more locations via the Internet.[6] This may involve commercial systems managed by health care organizations or personal communication software such as Skype. Besides clinical care, VC can also be used for continuing education.[23]

Support from a skilled multidisciplinary team is required to achieve the potential benefits offered by common diabetes-related technologies, with diabetes educators (DEs) being key members of this team. When considering CSII use, for example, they may help determine insulin dosage requirements, support achievement of therapy benefits, and mitigate the challenges and risks,[24,25] reported to be common with devices, associated consumables, and the user.[25] With little information how this occurs, this study aimed to examine DEs' perceived experiences, supports, and barriers to use of common diabetes-related technologies for people with T1D.

Methods

Design and Data Collection

This was a qualitative study undertaken from June to August 2014 using an ethnographic design. Data were collected by individual semistructured telephone interviews, allowing topics to be explored in depth, with confidentiality, providing opportunities to probe and encourage detailed responses, and enabling participation across wide geographical distances.[26]

The interview schedule was developed by research team members, and piloted with 2 Canadian-based DEs. Topics included participants' experience of working with each type of technology, the impact of supporting these technologies on workload, perceived supports and barriers to their use, and the influence of work environments on uptake and capacity. Participants were asked to briefly describe their professional background and geographical location.

Sample

A purposive sample was collected from members of the Australian Diabetes Educators Association (ADEA), the leading Australian organization for multidisciplinary HCPs who provide diabetes education and care. This sampling technique was chosen to obtain a wide cross-section of participants with collective experience with the 4 technologies. Participants were eligible for the study if they had current ADEA membership, current or past experience as a DE in Australia and in use of CSII, CGM, apps, and/or VC. They were required to be able to converse in the English language and have access to a telephone and an email address. Recruitment ceased when data saturation had been reached and it was deemed there were no new data to gather.

Procedure

A total of 213 members who responded to advertisements in the ADEA newsletter and completed an anonymous web-based survey (published elsewhere[6]) were supplied with study information and invited to participate; interested participants provided their contact details. Interviews were conducted by the first author, whose professional standing as a DE facilitated development of the trust necessary to share private, sensitive, or controversial details.[27,28] It also enabled understanding of participants' frame of reference, and potential exploration of contextual points or ideas raised. Personal preconceptions and biases were addressed through maintenance of a reflexive journal, peer debriefing, and triangulation.[29] Field notes were collected during and after each interview, which was audio recorded after an introduction where confidentiality principles were reinforced. Approval was obtained from the University of Technology Sydney Human Research Ethics Committee.

Data Analyses

Audio data and field notes were transcribed verbatim into Microsoft Office Word 2010, deidentified and imported into NVivo 10 software. Data were analyzed using Gibbs's[30] framework, which entailed transcription and familiarization, code building, theme development, and data consolidation and interpretation. Transcripts were available to participants for comment. They were read by all authors; the first author initiated coding and theme organization, which was developed and discussed with all authors to reach consensus.

Table 1. Interviewee Characteristics.

	n	Male	RN	APD	Age, mean (SD)[a]
Rural	6	2	6	0	48 (10.6)
Regional	9	0	9	0	53 (4.7)
Metropolitan	16	1	15	1	49.6 (5)
Total	31	3	30	1	50 (6.4)

APD, accredited practicing dietician; n, number; RN, registered nurse.
[a]Years.

Results

Interviews were conducted with DEs (n = 31) who worked across metropolitan, regional, and rural areas (Table 1). Most were female (90.3%) and registered nurses (96.8%), although working at differing levels of expertise and responsibility. Interviews lasted a mean (SD) of 35 (8.75) minutes.

Participants overwhelmingly perceived technology use as personally burdensome, when considering the increased demands that this placed on themselves and the need to occasionally use personal resources. Many wanted help, particularly to support patients with CSII. Three themes detailed perceived supports and barriers to involvement with common diabetes-related technologies in the care of patients with T1D: access to technology, availability of support, and technological advances.

Access to Technology

Access to technology was often difficult, both for patients and DEs. Patient access to CSII was limited by device costs, seen as prohibitive for many. The current Australian government subsidy, while considered beneficial, was not available to young adults, many of whom were unable to self-fund these devices. The absence of government CSII device support after age 18 years resulted in some patients being unable to replace and so continuing to use old and defective equipment. Participants felt obliged to support patients with minimally functioning devices, even though it was not seen as in their best interests:

> I had a chap the other week that didn't even have a face on his pump [CSII]. . . . He's still using it 6 months after I asked him not to. (DE-23:Metro)

Another barrier to access was the lack of systematic processes for determining the balance of benefit and risk from device use for individual patients. Often DEs were expected to take responsibility to gate keep this technology without formal organizational policy or professional guidance. As 1 DE stated,

> It's generally up to the DE who will see the patient first. They will deem if they think it [CSII] is suitable. (DE-53:Metro)

Similar access difficulties were described in relation to CGM technology. Participants, especially those working in hospitals, expressed frustration with their lack or limited access to CGM devices, transmitters and sensors, and that they often did not have adequate software and computer access to download CGM or CSII data direct from devices. They also perceived the cost of CGM technology as prohibitive to consumers, and appreciated when diabetes centers could fund CGM sensors. This occurred where DEs judged there was clinical need, a decision seldom underpinned by any formal policy or guidance. Where hospitals, and sometimes private DE practitioners, loaned CGM devices and/or transmitters to patients, this was seldom covered by a specific organizational infection control policy; devices were however routinely cleansed upon return. Highlighting cooperation between pediatric and adult diabetes services to increase CGM access in a regional setting, 1 DE stated,

> The pediatric unit actually paid for the device [CGM]. . . . I get the adults to pay for their sensors. (DE-92)

Difficulties with access were also described in relation to apps. Participants expressed their frustration that apps were not available across all brands and models of smartphones and tablets. They highlighted that many patients lack access to this technology and Wi-Fi coverage. However, this was also not provided to many DEs by their employers, and consequently they resorted to using their personal smartphones and Wi-Fi accounts.

Access to VC was mixed. Participants employed within hospitals, particularly in metropolitan areas, largely reported access to commercial VC systems, usually shared across health disciplines. However, the cost of such systems was prohibitive for smaller diabetes services, general practices and private DE practitioners. Instead, many participants in regional and rural localities used free personal communication software such as Skype. Originally banned, Skype use was now often approved. However, network coverage in nonmetropolitan areas was often erratic, especially outside of school hours, resulting in inconsistent visual and sound quality, and outages. This often deterred use.

Availability of Support

Time constraints were a barrier to participants' involvement with all technologies; CSII and CGM, particularly, were perceived to negatively impact workload. Recognizing the number of interactions required to commence a patient on CSII, 1 DE stated,

> We've got [small number] educators so if a person wants to go on a pump [CSII] you've got one educator out (ie, solely preoccupied with that patient) for a day and a half. (DE-22:Metro)

Participants expressed their frustrations at insufficient DE staffing for their patient numbers and lack of staff skilled in CSII and CGM, in particular. Considering the increasing

uptake, they were anxious how they would cope into the future, especially within pediatric settings. However they valued the support received from DE colleagues.

Participants also expressed their discomfort working with patients who had commenced CSII elsewhere, for the demands this placed on themselves and their already strained diabetes service. Many in regional and rural localities were suspicious that funding incentives from CSII companies, rather than patient needs, drove decisions to commence patients on this method of insulin delivery in metropolitan centers. Their concern was that these patients later sought follow-up, and in the event of related ill-health, presented to their local diabetes service or hospital, which was often understaffed and underskilled for this.

> Multiple metropolitan centers… would be happy to take a referral to initiate a pump [CSII], but that's the end of the service provided. (DE-11:Rural)

Limitations to Australian government Medicare rebates meant that many private DE practitioners were unpaid for much of the work they undertook. This acted as a barrier toward further involvement with CSII, CGM, and VC. One DE stated,

> The patients have to pay to see me or they had EPCs [enhanced primary care plans—government funding] that they could put through. I put in a lot of time and effort that I was never reimbursed for. (DE-9:Regional)

Managers and physicians could be supportive toward technology use, for example, by advocating for and securing related funding. However they could also act as barriers to involvement. Medical staff who had qualified from medical school years earlier were viewed particularly negatively when considering their views toward use of apps and CSII. Especially in community and general practice settings, little hands-on support was available to DEs for CSII and CGM use. General practitioners were perceived to have limited involvement in the care of patients using these technologies, referring any issues to DEs. Participants also highlighted endocrinologists' underuse and occasional unwillingness to use VC.

There was concern at lack of funding for on-call DE staffed services to provide advice in emergencies for CSII and CGM users outside of office hours: device failure, acute diabetes-related complications, and sick-day management, for example. In rare instances where on-call services were available, these were staffed by physicians with limited knowledge of these technologies. As a consequence, many participants provided selected patients with their personal contact details; criteria for such decisions were unclear:

> There's no point in them going to hospital because… they are not upskilled with using the pump [CSII].… If we can avoid an admission, I prefer to give them my personal mobile number. (DE-12:Regional)

Support was available from the manufacturers of CSII and CGM technologies through telephone help-lines for patients and HCPs. These were deemed very helpful by DEs, though concerns were raised at calls being diverted to agents in other countries and the sometimes "textbook" advice provided. Companies also loaned devices and transmitters, and provided consumables, trial sensors and ongoing education. However, for VC, participants identified very limited and sometimes complete absence of organizational training. They also had concerns about the support and facilities at connecting sites. Information technology departments were seen as both supportive and barriers to involvement with this technology.

Technological Advances

Participants had difficulty keeping up to date with advances in design and programming of CSII and CGM devices. They relied almost exclusively on information from companies. They struggled to maintain the regular software updates required for full functioning, in the face of barriers to downloading, organizational hurdles, and computer firewalls.

Similar difficulties were reported in keeping up to date with apps, especially because of their increasing numbers and the workload burden this represented. Participants primarily relied on obtaining information at conferences, but also from DE colleagues, companies, patients, and professional magazines:

> Everybody's so busy rowing the boat that they don't have time. Our flow through is not dropping, it's getting bigger… and you get less funding, less resources. (DE-27:Metro)

DEs were unable to make best use of data collected through apps and CGM systems. They highlighted concerns regarding the formats in which data were provided, based on programming deficiencies and the difficulties experienced interpreting such data. Patients were also not always good at providing complete information, with records omitting important details such as carbohydrate consumption and exercise undertaken.

> They send me information and you just can't work out what time it was and all sorts of things… it's not set out in a manner that is friendly for us. (DE-23:Metro)

Discussion

Our research provides important insights into DEs' experiences and perceptions of what supports and limits the use of common diabetes-related technologies for patients with T1D in Australia. Overall, themes demonstrated that while care was usually well-intentioned it was more often fragmented and inconsistent, and not often enough delivered with appropriate technology expertise. Change is clearly needed at multiple

levels of the Australian health care system to facilitate DEs' technology adoption and realization of the potential of these technologies for improved patient outcomes and support.

First, findings reveal that DEs need support to attain and retain the skills required to deliver these essential components of care. They mesh with findings from the anonymous web-based survey from which the sample derived (published elsewhere[6]), which highlighted the need for DEs' ongoing education to promote technology adoption. Though the support need around skills may lessen in the future with the generational ages of participants predominantly not indicative of "digital natives,"[31] in the meantime organizational and managerial support in the form of funding and time allowance (both study time to gain the skills and time to use them) would assist, as would rotating placements across and between pediatric and adult diabetes care settings. Besides increasing DEs' technology exposure, this may better align the norms of practice in different settings for greater consistency of patient experience.[6] Mentorship schemes should also be established and promoted; external stakeholders such as the ADEA may be able to assist.[32] They could also assist by providing periodic detailed summaries of evolving CSII and CGM systems and apps, in view of participants' difficulties keeping up to date. However while education is a necessary prerequisite, it is not a panacea.

Support for DEs in providing technology-based care delivery could involve service reconfiguration. In some areas this may necessitate reallocation of staffing and resources and improved infrastructure. Cross-coverage from areas where technology-based expertise exists would also assist, enabled by maximization of VC use. Besides facilitating DE peer support and professional development, VC could also be the medium to provide support directly for patients, to make communication more flexible and care more efficient.[23] Information technology departments have an important role in this, and access to such support should be maximized.

A review of policy and strategy is also required of the allocation of devices to patients, of the role of patients in choosing insulin delivery and glucose monitoring systems, and the processes for ensuring support from health care providers. The absence of consistent policies relating to CSII and CGM compounded the confusion reported both within and between services. Recent Australian CSII clinical guidelines feature assessment of patient suitability for CSII use,[33,34] and state guidelines make recommendations for in-hospital CSII care.[35] These should be promoted and adopted, and local policies formulated from these documents to translate guidelines into practice.

Australian government policy for access to common diabetes-related technologies, especially CSII, requires review. The current government CSII device subsidy ceases once a child reaches age 18 years.[16] However, considering the importance of optimal glycemic control to minimize diabetes complications, and hence their associated costs,[7,36] there is a case to extend the subsidy to enable CSII use to continue safely through the often impoverished early adult years when glycemic control often deteriorates.

Review is also required of the Australian government Medicare rebates available to private DE practitioners; lack of reimbursement was reported as a barrier to DEs involvement with CSII, CGM and VC. Existing rebates do not take full account of the time required to commence a patient on CSII, reported as median 18.6 hours and 14.1 interactions over 11.8 weeks.[33] Rebates only cover 5 'face-to-face' visits and do not fund consultations undertaken via VC although HCPs other than DEs are able to utilize this technology.[37]

Study limitations include that recruitment methods targeted only members of ADEA, and participants self-selected; findings may not be representative of all DEs.[38] There was no quantification of participants' experience with the technologies; limited exposure may have influenced perceptions. Nonetheless, strengths derive from the number of interviews undertaken, recruitment across diverse and wide sociological and geographical areas, and the depth and detail of data obtained on this little-explored topic.

Conclusions

This research provides important insights into the perceptions of an essential professional group in the care of patients with T1D, in relation to what supports and deters use of common diabetes-related technologies. Difficult access to technology, limited availability of support, and relentless but inaccessible technological advances influenced DEs' involvement. Findings suggest that to maximize technology adoption and support many DEs need to attain and retain the skills required to deliver this essential component of care. Furthermore, there is a need for review of policy and strategies, followed by reconfiguration of services to support care delivery and realize the potential benefits of these new but now common diabetes technologies.

Abbreviations

ADEA, Australian Diabetes Educators Association; app, smartphone and tablet application; CGM, continuous glucose monitoring; CSII, continuous subcutaneous insulin infusion; DE, diabetes educator; HCP, health care professional; T1D, type 1 diabetes; VC, video conferencing.

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Appendix 16: Interview schedule

Introduction.
As you are aware I would like to digitally audio-record the interview for accurate transcription of interviews. I would also like to get recorded verbal consent from you in relation to your participation so with your agreement I will now be turning on the recording device. I'm interested in exploring your experiences of use of diabetes-related technologies (insulin pumps, continuous glucose monitoring systems and telehealth via mobile phone and tablet applications, and video-conferencing) and what you perceive to support and hinder their use. A reminder that your participation is completely voluntary; you don't have to answer any individual question and you can stop the interview at any time without consequence. It is important to me that you provide truthful responses and I can assure you of confidentiality for your involvement and the responses that you provide. Any identifying details will be removed from the transcript so that it is permanently de-identified. Information you give us in the interview will be published in a form that does not identify you. I would however ask that you do not name anyone. Participant coding sheets, digital recordings and interview transcripts will be kept in a locked filing cabinet at a secured location until destruction. All members of the research team will have access to permanently de-identified interview transcripts. For record purposes, do I have your verbal consent to participate?
For each of the four diabetes-related technologies the following questions will be asked.
-What has been your experience of working with *the technology*? *Prompts if needed - can you tell me examples of individual patients/geographical*

distances/impact upon workload? -What do you perceive supports or enables you to use *the technology*, if anything? *Prompts if needed - are there things about the work environment/facilities/managers/skills?* -What do you perceive hinders or holds you back from using *the technology*, if anything? *Prompts if needed - are there things about the work environment/facilities/managers/workload/skills?*
Conclusion.
Before I finish are there any other thoughts about the use of the four technologies that you did not get a chance to share that you would like to share now? The information you provided was very valuable. Thank you for your time and contribution to the research project. Would you like a copy of the transcript?

Appendix 17: Participant information statement - semi-structured interviews

The following text was detailed at the end of the web-based survey (chapter 6):

Thank you for your time in completing this survey. As part of my research I'm also intending to explore in more detail Diabetes Educators' experiences of using diabetes-related technologies (insulin pumps, continuous glucose monitoring systems and telehealth via mobile phone and tablet applications, and video-conferencing) in patients with type 1 diabetes, and their perceived supports and hindrances towards their use.

If you have used any of these technologies and are presently based in Australia, you are invited to participate in a semi-structured telephone interview which is expected to take no longer than 30 minutes. I would like to digitally audio-record the interview for accurate transcription of interviews. You can change your mind at any time, not answer any individual question(s) and stop the interview without consequence.

To maintain confidentiality your interview will be tagged with a code number and not your name or details, which will be maintained separately in a coding sheet. Participant coding sheets, digital recordings and interview transcripts will be kept in a locked filing cabinet at a secured location. At the end of the research all documents and records except the transcripts will be destroyed. Permanently de-identified interview transcripts will be kept in a secure place for five years, and then destroyed. All members of the research team will have access to permanently de-identified interview transcripts.

Information you give us in the interview will be published in a form that does not identify you. If you agree to be part of the research, please provide the following details. I'll contact you to arrange a time for the interview that is convenient to you. If you have any concerns about the research please contact us via e-mail at Steven.B.James-1@student.uts.edu.au or Lin.Perry@uts.edu.au. If you would like to talk to someone who is not connected with the research, you may contact the University of Technology, Sydney's Research Ethics Officer on 02 9514 9772 or at Research.ethics@uts.edu.au and quote this number (UTS HREC approval number 2014000287).

Name: _____ **Telephone number:**

_____

E-mail: _____ **Date (DD/MM/YEAR): ____/ ____/ 2014**